

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

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## Update of Cancer Voices SA (CVSA) activity

### Now we are one.

Cancer Voices SA was officially launched one year ago in Nov 07. We briefly report on our activities and challenges in this first year.

CVSA are working hard to deliver benefits to South Australians (SA) affected by cancer through our activities around advocacy, involvement, awareness and information. We aim to change health systems to gain ongoing benefits to many people. We can't address problems specific to an individual case or deal with complaints.

CVSA members have been actively involved in many issues, meetings and forums, providing input on behalf of the SA cancer consumers/members. These include:

### Advocacy on issues:

- Radiotherapy under-dosing incident at the Royal Adelaide Hospital (see more later in this Bulletin),
- Chemotherapy over-dosing at the Womens and Childrens Hospital
- Coordinated, holistic and multi-disciplinary team approach to cancer care, and
  - Raise awareness of consumer interest in 'integrated medicine' with complementary therapies
  - Need for services including support after treatment has ended, support for carers after the patient has passed away, legal/financial

counselling (eg powers of attorney, wills, superannuation), sexual/sexuality issues, help for patients with a young family etc.

### Ongoing representation on:

SA Cancer Clinical Network (CCN) Steering committee, and the subcommittees/ working groups:

- Optimising Cancer Care Committee
- Cancer Information
- Radiotherapy Infrastructure Group
- Radiotherapy Performance Indicators working group,
- Complementary Therapies Working Party
- SA Quality and Safety Council in Healthcare Consumer Advisory Committee
- Cancer Voices Australia (CVA) Board
- Cancer Australia
- EdCAN Cancer Nurses
- CareSearch Palliative Care Reference Group

### Forums/Meetings/Workshops attended:

- Clinical Oncology Society of Australia - Consumer Forum (Nov 08, Sydney)
- Consumer Health Forum and Medicines Australia advocacy workshop for health consumer organisations (Nov 08, Canberra)
- National Institute of Complementary Medicine – Forum on information production, coordination, dissemination (Sep 08, Sydney)
- Workshop- Improving the availability, access and quality of cancer information for

clinicians and consumers (July 08, Adelaide)

- CaNET National Cancer Network workshops

### Presentations

- Southern Fleurieu Cancer Group,
- Cancer Council SA Cancer Support Group Leaders

### Media (see links at

<http://www.cancervoicessa.org/current-action>)

- Radiotherapy incident: Newspapers, TV news, ABC Stateline program, radio
- Chemotherapy dosing incident: Newspapers, radio
- CVSA cycling for cancer awareness: newspapers

### Documents

- CVSA Strategic Plan and Work Plan 2008-2010 (Feb 08) (see at <http://www.cancervoicessa.org/priorities>)
- CVSA Policies: (Feb 08) (see at <http://www.cancervoicessa.org/policies>) Actions Policy, Information Management Policy, News-Media and Speaker Policy, Representatives on Committees Policy, Rules of Incorporation, Website Content Policy,
- Radiotherapy benchmarks for cancer treatments, from the consumers perspective. (to CCN, Apr 08)
- Integrative oncology and Complementary therapies for cancer care in Australia and overseas. CVSA background paper. (to CCN, Jun 08)
- Cancer Advocacy Groups and Pharma Funding: CVSA discussion paper (to CVA, Jun 08)
- RAH cancer patient's Radiotherapy dosing errors – CVSA concerns (to Dr Tony Sherbon, July 08)
- RAH radiotherapy incident – CVSA concerns (to Prof Delaney, Aug 08)

### Newsletters

- Raising a Voice Bulletin
- Regular CVSA updates for Cancer Voices Australia newsletters and 'Mosaic', The Cancer Council SA Support Groups newsletter.

Advocacy isn't a 'quick fix' and there are many challenges. Sustainability of small, voluntary organisations is obviously one challenge. We need to grow and expand our capacity and supporters (see more later in this Bulletin).

CVSA are always seeking members and we need your ideas and feedback to keep us 'on track' and up-to-date with members issues and concerns. To do our job well we need to be representative of as many of the people affected by the disease as possible.

### Events

#### CVSA Cycle Team in the Tour Down Under – 23 Jan 09

Lance Armstrong is to start his cycling comeback in Adelaide at the Tour Down Under in January 2009. This provides an opportunity to promote Cancer Voices SA, raise our profile and gain extra membership through a "Cancer Voices SA" Team in the Tour Down Under Mutual Community Challenge.

Thanks to members who 'spread the word', we have a team of **121 riders** registered to ride with "Cancer Voices SA" on their jersey. The Community Challenge coincides with the Burnside to Angaston 'leg' of the Tour Down Under on Friday 23<sup>rd</sup> January 2009. It is not a race, and the team has cyclists at all levels of speed and ability in each of the 3 ride length options of 32, 97 or 155 kms.

#### Public Seminar in Feb 09

**Dr Eva Bezak**, the Chief Medical Physicist from the Royal Adelaide Hospital will give a public seminar titled "**Exposure to Radiation – it's not all bad news**". Eva will present information about the newest technologies as well as explaining how radiotherapy 'works' and why there are individual differences in the response to treatment. Don't miss this interesting and informative event upcoming in late Feb

2009. Details of the date and venue yet to be announced.

### **Advocacy Training in March 09**

CVSA, in partnership with The Cancer Council SA will run 'Consumer Advocacy Training' as 2-day courses on 14-15 March and 6-7 November 2009. This training will focus on *system advocacy*, seeking to achieve change to policies and practice rather than *self advocacy* or merely raising public awareness of an issue.

The program will include practical hands-on advocacy project planning and skills development as well as presenting an overview of the cancer world, finding and using cancer data, and understanding health systems and the policies at state and federal levels.

### **Outcomes**

#### **CVSA pressure influences national radiotherapy monitoring**

Introduction of National Radiotherapy Dosimetry Standards is one of the positive outcomes expected from CVSA advocacy around the Royal Adelaide Hospital (RAH) radiotherapy 'under-dosing' incident.

Cancer Voices Australia also assisted by lobbying at the national level for a Dosimetry Standards system. Medical physicists had been requesting this program for some time, but it took this incident and consumer lobbying to progress federal government interest.

Cancer Voices SA Executive demanded action to ensure better quality and safety systems and procedures are in place in all public and private radiotherapy facilities and expressed consumer concerns over the incident at a range of levels including with the media, the Chief Executive of SA Department of Health and Professor Delaney.

The independent Delaney Report made 14 recommendations for 'system changes' to address issues identified during the investigations. The Delaney review was

released on 10 Sept 08 and is available on the SA Health website [www.health.sa.gov.au](http://www.health.sa.gov.au). A second independent review was undertaken into the decision by the Royal Adelaide Hospital management to not notify patients, Central Northern Adelaide Health Service, the Department or Health Minister, when the error was discovered in 2006. Although the review by Mr Ian Kowalick found the response by the hospital's management was "reasonable" based on the information available at the time, a further 4 recommendations were identified and have been supported by the government. The Kowalick Report was released on 25 Nov 08 and can be found at

<http://www.health.sa.gov.au/Default.aspx?tabid=578>

Cancer Voices SA will continue to monitor implementation of recommendations of both reports to ensure they are implemented in full.

#### **Website Updated**

Liam Hunt has provided excellent website support for the CVSA team and has recently updated the site, introduced some YouTube links and lots more. Check out the changes at [www.cancervoicessa.org.au](http://www.cancervoicessa.org.au) !

#### **Cancer Clinical Network**

The six key activities of the SA Dept of Health Cancer Clinical Network are Cancer Prevention and Early Detection, Optimising Cancer Care, Infrastructure Planning, Workforce Planning, Cancer Research and Cancer Information.

Three 'pathways' are being mapped: for Lymphoma, Upper GastroIntestinal cancers, and Adolescents & Young Adults.

Cancer Voices SA members are providing consumer representation on the Cancer Clinical Network Steering Committee, Information, Infrastructure, Optimising Cancer Care sub committees, and the Complementary Therapies, Radiotherapy Infrastructure, Radiotherapy Performance Indicators working groups.

The Complementary Therapies Working Party is a sub-committee of Optimising Cancer Care, and is chaired by Ashleigh Moore. The group is currently reviewing a new booklet released by the Cancer Council NSW, called 'Understanding Complementary Therapies – a guide for people with cancer, their families and friends'. It is available at <http://www.cancercouncil.com.au/editorial.asp?pageid=1801>

Find more information about the Cancer Clinical Network at the SA Dept of Health website: <http://www.health.sa.gov.au/Default.aspx?tabid=213>

### CVSA Executive Team Vacancies

There are 3 vacancies on the CVSA Executive, so we invite 'expressions of interest' if you are interested in 'doing more' to help reduce the burden for those affected by cancer. Examples of sought-after skills could include marketing, communication, media or event planning to promote CVSA, 'grow' our membership, and communicate effectively. Tell us how you think you could contribute! The Executive meet once/month in the evening, with frequent email correspondence between meetings. Contact Ashleigh Moore for details. Ph 8291 4343 or [info@cancervoicessa.org.au](mailto:info@cancervoicessa.org.au)

We wish to say a big 'THANK YOU' and acknowledge the fantastic efforts of Marcus Beresford, Jennifer Pettigrove and Cholly Winter to help get CVSA established, and to Liam Hunt for website support. Jennifer has returned to Perth, Cholly to the Phillipines and Marcus and Liam have limited spare time. *"Good health and best wishes for the future"* to Marcus, Jennifer, Cholly and Liam from the Executive Team.

### Cancer Voices Australia - National update

Cancer Voices SA is a member of a national network of Cancer Voices, headed by Cancer

Voices Australia. The latest newsletter from Cancer Voices can be obtained at [www.cancervoicesaustralia.org.au/](http://www.cancervoicesaustralia.org.au/) detailing activities at the national level along with updates from each state. All members of Cancer Voices SA are included on the mailing list to receive this national newsletter.

### To contact us

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

Contact us by email to [info@cancervoicessa.org.au](mailto:info@cancervoicessa.org.au) or phone 08 8291 4343.

Visit our website at [www.cancervoicessa.org.au/](http://www.cancervoicessa.org.au/)

### Christmas Greetings and best wishes for the New Year



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