



Chairperson's Report – 2008-July 2009.

Welcome to the inaugural Annual General Meeting of Cancer Voices South Australia.

Our motto is: 'Raising a voice for those affected by cancer in South Australia', through

- **Advocacy,**
- **Involvement,**
- **Awareness**
- **Information.**

After our official Launch and Consumer Forum in Nov 2007, we commenced a Strategic Planning process incorporating feedback from the 'Consumer Forum' and issues raised in our Consumers Survey (Nov 2006). We determined that action was required in 5 'Key Result Areas' to establish Cancer Voices SA on a firm 'organisational' footing by 2010. Strategies proposed within these Key Result Areas (for the period 2008-2010) were:

Advocacy

1. Representation, Involvement, Strategic Engagement
2. Campaigns:
 - 1 Holistic and Multidisciplinary Team approach to cancer treatment
 2. Human Papilloma Virus HPV and cancer awareness

Promotion & Communication

3. Membership drive
- 4 Newsletters
5. Website

Events

6. Member meetings and AGM
7. Consumer Forums
8. Survey members for issues annually

Training & Capacity Building

9. Executive
10. Members

Management & Administration

11. Membership registration and communication
12. Executive operations
13. Reporting and accountability

With the Strategic Plan in place, we proceeded with Advocacy activities through representation on various state and national committees. This was consistent with our aims to **represent** the views of those affected by cancer; and **promote** these perspectives to health professionals, government and the public. We also worked hard on developing a comprehensive set of Cancer Voices SA Policy documents.

A steep 'learning curve' began from mid-late 2008, following newspaper reports of several 'incidents' involving cancer patients ie. radiotherapy and chemotherapy dosing errors. This prompted Cancer Voices SA to respond and address the broader concerns, not just the specific problems reported in the media; this tested our resolve to 'Raising a Voice'. Cancer Voices SA is now maintaining the pressure to ensure recommendations of the Delaney, Kowalick and Commuio Reports following these 'incidents' are implemented in full.

In late 2008, Cancer Voices SA commenced a novel cancer-awareness and membership promotion drive by inviting cyclists to join a team to ride in the Tour Down Under Community Challenge Ride. Cancer Voices SA came to the attention of the Lance Armstrong Foundation and LIVESTRONG staff through engagement via Twitter, and managed to meet and establish a relationship with this global cancer advocacy organization. The Cancer Voices SA cycling team recruited 123 riders, many of whom were closely 'affected by cancer'. This was the largest team in the history of the Tour Down Under Community Challenge. We saw, and seized

the opportunity for cyclists to raise attention before, during and after the Challenge Tour ride by wearing the Cancer Voices SA name on their jersey, and through media interest in cancer being heightened by the presence of Lance Armstrong riding in the Tour Down Under in Adelaide.

Three areas were flagged for 'Priority Activity' for Cancer Voices SA in 2009:

- **Advocacy: Representation, involvement, strategic engagement**
- **Promotion and Communication: Membership drive**
- **Training and capacity building: for members and the Executive team.**

We had about 70 members of Cancer Voices SA at the end of 2008. We recognized the importance of 'growing' and attracting members representing all age groups, types of cancer etc., in line with our key objective to "ensure those affected by cancer are treated equally regardless of :

- geographical location
- social or economic status
- age
- ethnicity
- sexuality
- gender
- stage or type of cancer".

Our membership doubled as a result of the cycling initiative, with media attention and 70+ members joining the cycling team. Growth has continued to our current total of around 270 members. The cycling team is training for the 160km 2010 Tour Challenge Ride from Norwood to Goolwa. Related to cycling, we gratefully acknowledge the generous support of 12 volunteers who 'manned' stations during the 'Coast to Coast' (Glenelg to Victor Harbor) bike ride in March, which earned us a small Community Participation Grant.

It is important to note that we are not just focusing on the number of members. We also want to ensure that we are involving, engaging, able to listen, have discussion with, and inform members. Quality and quantity of engagement is our goal. Development of the Cancer Voices SA website is ongoing as a source of information and communication, to "*ensure patients and supporters are receiving the best possible information, treatment and care*". It is regularly updated with news and resources. We welcome suggestions and feedback from members. The website will increasingly become the main source of information provision and communication. Around 97% of members have access to email /internet. This is also the only quick, efficient, cost-effective means of operation for a small volunteer organisation without staff or premises.

In March 2009, the first Cancer Advocacy Training course was held in South Australia, in collaboration with the Cancer Council SA. The inaugural 2 day course attracted 13 participants who all rated the training as 'Excellent' and very worthwhile. This is an important step towards 'capacity building' of the Executive Team, and an opportunity for general members to gain skills to become more involved. The 2-day course will be run again in November 2009.

Key issues raised in our Consumers Survey were around poor communication, coordination and information about cancer care, complementary therapies, access and cost of new treatments not listed on the Pharmaceutical Benefits Schedule (PBS). Through the work of Cancer Voices SA representatives on the Cancer Clinical Network, progress is being made towards achieving holistic and multidisciplinary team care with better communication between cancer clinicians. A Complementary Therapies Working Group has been established, chaired by Cancer Voices, with clinicians, complementary therapists and cancer patients. National issues, such as cancer drug listings on the PBS eg Avastin, Herceptin and the current Intravenous Chemotherapy Supply Program, are being actioned by Cancer Voices Australia, with input from Cancer Voices in each state on the Board of Cancer Voices Australia.

Cancer Voices SA involvement in several 'Global Cancer Initiatives' commenced in April 2009, with a series of 'Cancer Conversations' being held as part of the Campaign 2 Control Cancer Initiative. This Initiative is a collaboration between the International Union Against Cancer (UICC), Canadian Cancer Control organization and LIVESTRONG (the Lance Armstrong Foundation). Cancer Voices SA were keenly exploring means to communicate more closely with our members, to hear their issues and concerns, and this Global Cancer Initiative provided tools and support to help us achieve this. A report collating all 300+ Cancer Conversations held around the world will be completed and presented at a Forum in Canada in September

2009. This Initiative provided the opportunity to commence engagement with Aboriginal groups, for whom cancer outcomes are trailing far behind the general population.

Another international Initiative taken up by Cancer Voices SA is the LIVESTRONG Global Cancer Campaign. This was launched in Adelaide during the Tour Down Under, and is being promoted world-wide by Lance Armstrong's return to the Tour racing program. The 3 major goals of the Global Cancer Campaign are:

- Together, to **end the stigma of cancer** (turn victims into survivors)
- Together, to **build an international grass-roots movement** (move cancer from isolation to collaboration)
- Together with world leaders, **shift cancer from obscurity to priority.**

Cancer Voices SA has submitted 4 commitments to undertake activities aligned with these goals, and have been awarded 4 travel scholarships to attend the 'invitation only' Global Cancer Summit in Dublin in August.

Challenges/ Issues encountered:

Advocacy isn't a 'quick fix'. It can be a 'very lonely place', and there are many other challenges. Sustainability of small, voluntary organisations is obviously one big challenge. We need to grow and expand our capacity and supporters.

We need funding, but do not want 'fund-raising' to become a focus in itself which diverts our energy and attention from our key objectives of 'raising a voice' and representing those affected by cancer in South Australia.

The workload of the Executive Team is substantial, and a number of members have been unable to maintain this role alongside a busy family life and career. We need to adequately support active members so they can be effective, informed, efficient, and stay well – physically and emotionally.

CVSA are always seeking members to contribute 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 this disease as possible. We'd appreciate all members assisting in promoting Cancer Voices SA.

In conclusion,

We are proud of our achievements since being Launched in Nov 2007. An active and exciting time is ahead. We are the 'people affected by cancer', and because of this, we have a unique perspective of all aspects of the cancer journey. This is not a '9 to 5' job for us, and on behalf of the Executive Team, I can assure you that we are all passionate about 'making a difference'. Find further details about Cancer Voices activities listed at our website: <http://www.cancervoicessa.org.au/achievements.asp>, and updates appear in our 'Raising a Voice' Bulletins.

Ashleigh Moore
Executive, Cancer Voices South Australia
28 July 2009

"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." LIVESTRONG

"we're not doing enough, fast enough. It is time for a call to action and a concerted effort to start leveraging public concern and commitment in order to shape and support new programs, policies and principles for cancer control." Global Campaign to Control Cancer.

Acknowledgements:**Cancer Voices SA Executive Team members since 2007-July 2009**

Ashleigh Moore	Executive, Chairperson
Cholly Winter	
David Chapman	(Resigned) Deputy Chair, Treasurer
Jim Vlahakis	
Jennifer Pettigrove	(Resigned)
Julie Marker	
Liam Hunt	
Louise Murada	(Resigned)
Marcus Beresford	(Resigned) Public Officer
Maria Adamczak	
Pam Sandys	Secretary
Suzi Tonner	(Resigned)
Vince Riviere	

Summary of Cancer Voices Activities, 2008 – July 2009..**Advocacy:****Representation on:**

- SA Cancer Clinical Network (CCN) Steering committee and the following subcommittees/working groups:
 - Optimising Cancer Care subcommittee
 - Cancer Information subcommittee
 - Infrastructure subcommittee
 - Radiation Oncology subcommittee
 - Radiotherapy Performance Indicators working group,
 - Complementary Therapies working group (chaired by CVSA Exec)
- SA Quality and Safety Council in Healthcare Consumer Advisory Committee.
- [Cancer Voices Australia](#) (CVA) Board.
- [Cancer Australia](#) - National Consumer Advisory Committee.
- [EdCAN](#) - Cancer Nurses Education Project.
- [CareSearch](#) - Palliative Care National Advisory Group

Advocacy on issues:

- Radiotherapy under-dosing incident at the Royal Adelaide Hospital
- Chemotherapy over-dosing at the Womens and Childrens Hospital
- Management of multi-drug-resistant organism risk for oncology patients. [Draft Position Statement](#) presented to the Safety and Quality in Health Care Consumer and Community Advisory Group.
- We are Monitoring implementation of [Communio](#), [Delaney](#) and [Kowalick](#) report recommendations on cancer services, and reviews following the radiotherapy and chemotherapy treatment incidents.
- Multidisciplinary team care is being progressed and integrated into cancer pathways, through representation via the Cancer Clinical Network (CCN), and Holistic care via CCN Complementary Therapies Working Group (CTWG).

Documents to support Cancer Voices position on issues

[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).

Involvement:**Cancer Conversations:**

Cancer Voices SA held 10 [Cancer Conversations](#) during Apr-May, and reports of these Conversations have been submitted to the Global Cancer Initiative, [Campaign 2 Control Cancer](#).

Global Cancer Campaign:

In June, Cancer Voices SA submitted 4 [commitments](#) to the LIVESTRONG [Global Cancer Campaign](#), and CVSA representatives have been invited to attend the Summit in Dublin in Aug 09.

Forums/Meetings/Workshops attended:

- LIVESTRONG [Global Cancer Campaign, Launch](#) (Adelaide, Jan 09)
- [Cancer Advocacy Training](#) (Adelaide, Mar 09)
- 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.

Cancer Research

Consumers involved in research proposal development and funding review.

Awareness

Presentations:

[Cycling In Medicine Conference](#) (Jan 09)
Rotary - Adelaide Branch (Feb 09)
Asbestos Diseases Society of SA [ADSSA](#) (Mar 09)
[Payneham Prostate Cancer Support and Awareness Group](#) (Jun 09)
Mitcham Prostate Support Group June 09
Aboriginal Healthcare Workers Forum (Jul 09)
Southern Fleurieu Cancer Network – Launch (2008)
Cancer Australia - CanNet Multi-disciplinary Care Forum (2008)
Cancer Council SA - Support Group Leaders Development Forum (2008)
Southern Fleurieu Cancer Network - Update (2008)

Media:

[Cancer Voices SA cycling for cancer awareness](#): TV: A Current Affair Ch9 Adelaide (Jan 09), Messenger Newspapers (Jan 09).
Radiotherapy incident: Newspapers, TV news, ABC Stateline program, radio.
Chemotherapy dosing incident: Newspapers, radio.
CVSA cycling for cancer awareness: newspapers.

Cancer Voices SA [Cycling Team](#)

- 123 riders in Tour Down Under Mutual Community Challenge ride (Jan 09)
- 20+ riders in the Coast to Coast ride, and 12 volunteers supported BikeSA to run the event. (Mar 09)
- 70+ members registered in the Cycling Team.

Information

Website, email alerts/ notifications to members
Newsletters and contributing articles in other organisation's newsletters:
'Raising a Voice' *Cancer Voices SA news-bulletin*
[Raising a Voice - July 09, December 08, August 08, June 08](#)

Cancer Voices SA articles in [Mosaic](#), the newsletter for Cancer Council SA Support Groups
[March 2009](#); [October 2008](#); [March 2008](#); [August 2007](#); [May 2007](#); [March 2007](#)

Cancer Voices SA newsletter articles in:
[Prostate Supporter](#) (Prostate Cancer Support Groups SA), July 2009
[Aboriginal Legal Rights Movement](#) Newsletter, June 2009 (page 7)