

## **CANCER VOICES AUSTRALIA REPORT - November 2007**

Cancer Voices Australia is the national consumer organisation representing Australians affected by cancer. It aims to ensure the voices of people affected by cancer are heard at a national level. Our objectives are:

- To promote the fundamental rights of Australians affected by cancer
- To effect improvements in cancer treatment, care and support by contributing to national cancer policy and program development, management and evaluation
- To promote the value and benefits of consumer participation in the development of national cancer policy and programs
- To provide a forum for member organisations to network and contribute to national activities

CVA was incorporated on the 29<sup>th</sup> September 2006 and formally launched on February 4<sup>th</sup> 2007 – World Cancer Day.

### **Year in Review**

All Australians, regardless of location, income or age, have the right to worlds best practice cancer care which includes. CVA has advocated for and succeeded in mounting change:

#### **Multi-Disciplinary Care**

- The worlds best practice cancer care is Multidisciplinary Care (MDC). MDC is acknowledged internationally as the best and most effective way to treat cancer

Success (but more work needed) - Now 64% of cancer patients are treated by a multi-disciplinary team

#### **Availability of new Cancer Therapies**

There is a need for greater transparency and consumer involvement in decision-making processes regarding new cancer therapies and their availability.

- Industry links of clinicians, and others, lobbying for new cancer drugs to be on the PBS or for other therapies to be available should be public knowledge.

- Consumers must be involved in the decision making process.
- Approved therapies for a particular cancer should be available on the PBS or funded through Medicare or by the states and territories.

Success – Patient Impact Statements are to be part of the PBAC process

### **Travel and Accommodation Access**

All cancer patients in this country should receive access to the same travel and transport scheme entitlements regardless of their state or territory.

- Funding for isolated patients is one of the longest running health issues in Australia. Numerous studies and reports have recommended changes to the system to ensure that patients who travel to state capitals for treatment over many weeks or months receive sufficient funding.

CVA welcomes the recent Senate Report on its Inquiry into the 'PATs' Schemes.

### **Reforms to Superannuation**

The existing and proposed laws relating to the taxation of superannuation benefits: unreasonably disadvantage the terminally ill and others living with life threatening illnesses; exacerbate the financial stresses they face; and hamper their ability to put their affairs in order before death.

Access to superannuation represents the best chance for these terminally ill cancer patients to bring some semblance of financial order to their lives; to pay for medical costs and transportation, to meet at least some of their debts, and to meet ordinary living costs for themselves and their families when they have no other income. Early access to superannuation also provides an opportunity to order affairs and pay off debts before death, instead of leaving this task to a grieving family. The current laws relating to access to superannuation are very strict indeed and the taxation component payable by a terminally ill cancer patient if they receive approval to access their funds prior to their death are taxed at the marginal rate.

Success – In September 2007 a combined effort of consumer groups and the consumer face persuaded the Federal government to introduce legislation to enable terminally ill patients access to their Superannuation entitlements – tax free.

More to Do – People who are so seriously incapacitated that they are unable to work full time also need access to their superannuation entitlements so that they can pay the debts they accumulate during treatment and as they continue life. Cancer Voices will be working on this problem during the coming year.

### **The Role of Governments**

The continuing issue remains - where does responsibility for cancer in Australia lie - with the Australian Government or with the state and territory governments?

In the past decade many national reports have highlighted the gap between the Australian Government and its Dept of Health & Ageing and what are known as “the jurisdictions” – the state and territory health departments. National reports consistently and accurately identify the problems but the chasm between the Australian Government and the states and territories in terms of ‘action’ prevents effective resolutions. The result is limited progress and cancer patients not being provided with well co-ordinated multi-disciplinary care. The current structure contributes towards what is described as “The Cancer Lottery”.

Whichever party wins the election, Cancer Voices and its partners will have much to do to improve the health and cancer systems in the coming year.

### **Federal Government - Cancer Australia**

The Australian Government’s initiative in setting up Cancer Australia provides a threshold for effective change, hopefully at all levels of government and with support from the non-government sector. It is essential that Cancer Australia remain well funded otherwise fundamental changes will be unachievable.

**We applaud the foresight shown by the Howard Government to establish this body and CA’s ‘mantra’ to include consumers as its integral part of the cancer process.**

### **ACTIVITIES**

#### ***Representation***

At year end CVA had representation on 65 boards, committees, and working parties at the International, and federal and State government level. Their

representation is in their own capacity or as a CVA spokesperson so all are well equipped to represent consumer views.

### ***Campaigns***

PATS - a national campaign for the improvement of the PATS resulted in the 2007 Senate Inquiry into this matter. We eagerly await government action on this report.

Superannuation – see above

Capital Equipment - lobbied the Federal government to provide more radiotherapy machines. In September the Govt approved expenditure for 13 MRI's across the country.

Access to Targeted Therapies – supported other cancer groups in their endeavours to achieve PBS listing for drugs for cancer patients.

### ***Speaking Engagements***

A number of the CVA Executive has spoken at International, National and state cancer related conferences and seminars. Many have also been interviewed for print, TV and radio media. Letters to the editor were also published on issues of the moment pertinent to our work.

### ***Policy Engagement***

CVA has participated in the policy development of Cancer Australia, The Radiation Working Group, Clinical Trials Registry, The therapeutic Goods committee, and National Bowel Cancer Screening. CVA has made or partnered submissions to PATS Senate Inquiry, Privacy Commission,

### ***Partnerships***

CVA has established solid working relationships with the stakeholders with which it works. It has overcome some difficulties associated with its constitution and steps to improve relations may be addressed by a change in constitution. This matter will be dealt with at the AGM.

### ***Executive***

The Executive has worked hard to first establish and raise the profile of CVA. It resolved to elect interim chairs from the established CV's organizations. Thanks go to David Sandoe, Leonie Young and Ian Roos for their leadership. Heavy work commitments for David Sandoe saw him resign from CVA in April. Due thanks and appreciation is accorded to Ian Roos who undertook the dual roles of Chair of CVVic and that of CVA to steer the organisation through a

difficult period. CVA acknowledges his input and dedication to the consumer cause.

The Executive has met via teleconference every six weeks, and held a National Forum in August 2007 attended by representatives from CV's and other supportive cancer consumer groups.

John Stubbs, Executive Officer (part-time) has continued to drive CVA's agenda.

### ***Membership***

The membership of CVA is limited to its state Cancer/ Voices organisations. The year in review has seen the formal launch of Cancer Voices in Victoria and QLD. Cancer Voices SA will be formally launched at COSA in November. Following a restructure in Tasmania, CV TAS is working towards incorporation and official launch in 2008

### ***Financial Statement***

The Financial Statement for the period is attached to this report.

### ***Acknowledgements***

CVA would like to acknowledge the cooperation and support of:

The Cancer Council Australia

COSA

The State Cancer Councils

NBCC

BCNA

Cancer Institute NSW

Kenneth Gray Partner Baker & McKenzie Melbourne (Superannuation reform)

Prostate Cancer Foundation Australia

Brain Tumour Australia

LungNet

In conclusion I would like to acknowledge the courage and strength of the cancer community, many of whom have contributed to the success of CVA's agenda.

John Newsom

Chair

November 2007