

Cancer Voices Australia NEWS UPDATE

October 2014

Parliamentarians Supporting Cancer Causes – Event with Cancer Voices

The launch of the new **Australian Cancer Consumer Network (ACCN)** of 28 participant groups takes place on 26 November. Those participating in the first *Who's Who* directory of cancer consumer groups have been invited to meet federal politicians attending the event at Parliament House, Canberra, co-hosted with CVA.

Twenty years anniversary of cancer consumer advocacy in Australia: 1994-2014

Cancer Forum's November issue carries an invited Letter outlining the movement's history, efforts and achievements on behalf of people affected by cancer. This will be posted on the CVA website. The anniversary will also be celebrated at the event above, and in an address at the University of Sydney.

Patentability of Human Genes – What now?

The negative Federal Court decision handed down on 5 Sept was a disappointment to cancer consumers, researchers and clinicians. CVA has decided to follow the Judges' comment that the principle "...is not a matter for the court, but for Parliament to decide". We will work with concerned politicians of all parties toward amending the Patents Act 1990 to reflect the community's concern about this anomaly.

Lymphoedema Action Alliance (LAA)

A national alliance of 10 organisations, the LAA is to be launched in Sydney on 15 October. Consumers are seeking development and adoption of guidelines, and the inclusion of lymphoedema garments in Medicare. People with a range of cancers have to live with this debilitating treatment-caused condition.

NHPA Cancer Surgery Waiting times: See www.nhpa.gov.au

The National Health Performance Authority has released lists of public hospitals in all states which met waiting time limits (30, 45, 60 and 90 days) for breast, bowel and lung cancer surgery in 2012-2013. CVA participated and responded to media interest. Consumers are urged to check outlier hospitals and bring them to the attention of their Departments of Health. Good news was that rural hospitals' performance was similar to metropolitan.

Cancer Research in Australia 2006-2011: Cancer Australia

CVA welcomes the release of this necessary audit, and participated in media comment. It highlights the lag for less common cancers in attracting research dollars – 20% of funding with 50% of deaths.

Consumers attending cancer conferences

The National Breast Cancer Foundation has answered the call to support attendance of consumers at national and, indeed, international cancer related conferences. We hope other funders and agencies will do likewise so that consumers can be kept up-to-date and benefit from important networking opportunities. Cancer Voices will be attending the COSA ASM in Melbourne in December, but largely at its own expense.

Matching services for policy, service and research decision-makers: see www.cancervoicesaustralia.org

In NSW, training courses for consumer in representation/ advocacy and involvement in research have resulted in a bumper crop of new keen "graduates". Almost 70 have joined the matching databases. We are seeking updates from the other states in this field, so eventually there can be linked national databases.

More recognition for Cancer Voices' work: CVA convenor Sally Crossing was a winner among the Australian Financial Review/ Westpac's *100 Women of Influence Awards* announced on 1 October.

Cancer Voices Australia is the independent, the volunteer voice of people affected by cancer - since 2000.

