

Cancer Voices Australia NEWS UPDATE

February 2015

Survivorship Conference 2015 <http://www.survivorship2015.org>

Cancer Voices' Sally Crossing gave the inaugural Ashleigh Moore Memorial Oration on 6 Feb at the FCIC Survivorship Conference in Adelaide. This honours Cancer Voices SA's Founding Chair and his huge contribution to cancer consumer advocacy. The conference benefited from strong input by consumers. Cancer Voices SA representatives assisted in the planning, chaired sessions gave presentations and posters. See links at <http://www.cancervoicesa.org.au/awareness/community-noticeboard/2015-survivorship-conference>

Cancer Survivors' National Survivorship Framework: Consumers are now calling a high level statement about best practice survivorship for people diagnosed with cancer and their carers. It should address what to expect and how to navigate through the post diagnosis cancer journey and beyond. The Framework will also help health professionals, including cancer specialists and allied health providers. This kind of guide is the basis for accreditation of cancer centres in some other western countries and is greatly needed here. See Position Statement on CVA website, once consultation has been finalised (end Feb).

Better access to cancer drugs: Cancer Voices, ACCN groups and the CHF made submissions to the Senate Inquiry into *Availability of new, innovative and specialist cancer drugs in Australia*. Cancer Voices submission is on our website. It and others will be viewable on www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Cancer_Drugs.

Gene Patent Appeal to be heard by High Court: This Appeal (mid-April) follows the 2014 Full Federal Court judgment that upheld the validity of the patent in relation to the BRCA1 gene associated with hereditary breast and ovarian cancer, contrary to USA decisions.

CVA contributions to current Reviews: Review of Medicines and Medical Devices, PBS Medication Charts for Public and Private Hospitals Initiative; MSAC – IMRT & IGRT Agenda Items; Orphan Drugs Review; NHMRC Clinical Trials Portal; National Cancer Control Indicators; National Bill for Regulation of Medical Cannabis. The Sixth Community Pharmacy Agreement consult is due to commence soon.

Consumer Involvement in Research: Cancer Voices is participating in the development of Consumer Online Training for involvement in research with the NBCF and the Cancer Council NSW. We are also active in the review of the NHMRC's portal to clinical trials. The CV "matching" service continues to link researchers with suitably skilled consumer reps.

Consumers attending cancer conferences

Our call for a few registration free places to enable unsalaried cancer consumers to attend relevant conferences continues. So far this year, it seems this will only occur when we are invited to be Speakers. This is not adequate our mutual goal with stakeholder is real consumer engagement. See Position Statement on CVA website.

Recent Publications

ACCN's 'Who's Who' 2014 Directory – see <http://www.cancervoicesaustralia.org/accn/>. Now widely distributed, also available on request in electronic format via info@cancervoices.org.au. As a summary of the Australian cancer consumer movement's first 20 years which appeared in *Cancer Forum's* Nov.2014 issue: http://www.cancerforum.org.au/file/2014/November/13_Letter.pdf