

Cancer Voices Australia NEWS UPDATE

April 2014

Access to cancer drugs www.cancerdrugsalliance.org.au

Cancer Voices and 16 cancer consumer groups and other organisations which advocate for people affected by cancer, took part in a two-day Stakeholder Forum in Canberra, 26 & 27 March. Hosted by the Cancer Drugs Alliance (CDA), the gathering of clinicians, industry, government and consumers, examined ways to ensure our HTA approvals processes, especially those for PBS subsidised drugs, better reflect both the specific characteristics of cancer drug development and those of cancer patients.

Establishment of Australian Cancer Consumer Network (ACCN).

Building on the framework of CVA's own cancer consumer network established last year, a wider national level cancer consumer network has been facilitated through CVA. The impetus for this was the opportunity to meet face to face at CDA's Stakeholder Forum, where the need for an independent consumer collaboration to provide *a more effective consumer voice on national issues* was clearly recognised. While access to drugs is a first priority, the new network (27 participant groups to date) will be able to address other important issues, support each other and share information. A catchier name may be found!

Guidelines for coordination of cancer care

Our efforts towards recognition of the need for best practice guidelines for coordination of cancer care, throughout the cancer journey, but especially at end of life, are gaining traction at last. CVA is to meet with Cancer Australia (CA) senior staff in May to discuss options, noting the outcomes of the recent COSA and Cancer Institute NSW conferences on the topic.

Chemotherapy Funding Review

All welcomed the Government's interim \$82m package which covers the situation until 1 July 2015. We understand that future funding will come under the next Community Pharmacy Agreement (6CPA). CVA joins other stakeholders in calling for the parties to the upcoming 2014 6CPA negotiations to be broadened beyond Government and the Pharmacy Guild of Australia, the pharmacists' union, to include community interests.

Security of cancer drug supply

This continues to concern us on two counts. (i) when pharma decide not to continue supplying a drug already on the PBS, and (ii) when they discontinue Special Access support due to failure to get PBAC approval for a drug. Both can leave patients and their clinicians in difficult and distressing situations.

CVA submissions on Health Technology Assessments, Guidelines and Inquiries

CVA has made several submissions, sometimes in support of network members, on several HTA agenda items – both for PBAC and MSAC. We also provided comment on two Cancer Australia Draft Guidelines and Government Skin Cancer and Out of Pocket Costs Inquires.

CVA welcomes the new Parliamentary Friends Cancer Group.

Co-Chair, Sen. Deb O'Neill has welcomed our regular raising of issues of interest and concern for Australians affected by cancer. Dan Tehan MP from Victoria is Co-Chair and opened the CDA Stakeholder Forum.

Vale Ashleigh Moore OAM

Cancer Voices deeply misses one of its leading lights, Ashleigh Moore, who died on 3 Feb. Ashleigh was Chair of Cancer Voices SA and contributed greatly to numerous national committees. See a tribute to him at www.cancervoicesaustralia.org.au/awareness/community-noticeboard/ashleigh-moore-oam-rest-in-peace

