

Cancer Voices Australia NEWS UPDATE

October 2015

The last two months have seen greatly increased positive activity around issues for which we have advocated strongly during 2015. The voices are being heard!

High Court decision re Human Gene Patenting

Cancer Voices, and many other health consumer groups, clinicians and researchers, have welcomed the positive 7 October decision. Cancer Voices has been engaged in this via its membership since 2001. We thank Yvonne D'Arcy for staying the distance and Maurice Blackburn for their unwavering support. Good sense prevailed. See decision at <http://www.hcourt.gov.au/assets/publications/judgment-summaries/2015/hca-35-2015-10-07.pdf>

Better access to cancer drugs:

Cancer Voices welcomed the report of the Senate Inquiry report on *Availability of new, innovative and specialist cancer drugs in Australia*. We have asked the Minister for Health to pursue the three major recommendations:

- Increased consumer involvement in all aspects of PBAC decision-making, and in any review of the registration and subsidisation processes
- Improved flexibility in regulations around the access and analysis of data, particularly combined MBS and PBS data
- Establishment of a national register of cancer drugs to ensure we can make assessment of their value

See http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Cancer_Drugs

Regulating production of, and access to, medical cannabis: Good news: following the positive Senate Inquiry report on the Regulator of Medical Cannabis Bill 2014, the Government has announced that it will introduce legislation re production licences before year end. Cancer Voices remains concerned that immediate access to appropriate quality products has not yet been addressed.

Priority issues for Australians affected by cancer: Results of the 2015 survey of the 30-strong Australian Cancer Consumer Network will be used to inform our representatives in the lead up to the coming federal election, and to advise cancer agencies and charities about priority issues for Australians affected by cancer.

Cancer Australia's Principles of Cancer Survivorship: Cancer Voices welcomes Cancer Australia's project after advocating for this over the past year. Consumer views, outlined in the CVA Statement on our website, will be represented on the Steering Committee. CVA has also joined CA's Intercollegiate Advisory Group.

Travel insurance for cancer patients: CVA has received a report from the Insurance Council of Australia about the complex situation re insurance for people affected by cancer (experienced previously or currently). We will shortly meet with interested insurers.

Implications of chemo under-dosing in SA

Media interest has highlighted the need for quality & safety standards for the delivery of chemotherapy in both public and private sectors. Cancer Voices SA has participated in the review chaired by Prof Willis Marshal.

Consumers attending cancer conferences: Encouraging initial discussions with the Royal Australian & New Zealand College of Radiologists (RANZCR) about offering a limited number of registration free places to its 2016 Annual Scientific meeting. Cancer Voices SA reps will contribute to some sessions at the 2015 ASM in Adelaide. We are hopeful that other cancer professional organisations will soon follow this example of real interest in the consumer involvement. CVA has had two poster Abstracts and one mini oral presentation accepted for the COSA ASM Conference in November, posted on our websites. Four CVA reps will be attending at reduced rates.

Recognition: Congratulations to Dan Kent, cancer consumer advocate from Bundaberg QLD

Who won the inaugural John Zalberg OAM Award for Excellence in the Australasian Gastro Intestinal Trials Group (AGITG). Dan has been the current Chair of the AGITG Consumer Advisory Panel (CAP) since 2011 and a member of the inaugural CAP since it formed in 2008, among many other consumer rep positons.

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