

Cancer Voices Australia NEWS UPDATE

November 2016

Safety & Quality in Cancer Care: 2016 chemotherapy dosing “incidents” in South Australia and NSW led us to call for development of Best Practice Clinical Standards. Cancer Voices has formally expressed concern that public confidence is not helped by processes which rely on whistle-blowers and leaks to know if their treatment may have deviated from best practice.

In NSW we have made a submission to the Legislative Council Select Committee which is holding an *Inquiry on the off-protocol prescribing of chemotherapy*. Our submission can be viewed on their website. We are hoping to participate in NSW Health’s related *Review of Cancer Care in NSW Public Health Facilities*. However to date nominations have been called from the five professional organisations (AMA, COSA, College of Surgeons, RANZCR and MOGA) and the Cancer Institute, NSW but not from that represent people affected by cancer – Cancer Voices. Cart before the horse?

Canberra Forum 18-19 October – “Disrupting Cancer”: Hosted by Rare Cancers Australia, 130 guest including consumers, public servants, scientists, researchers, clinicians, industry reps and politicians considered the hot topics for people affected by cancer. Two major highlights were the keynote address by Health Minister Sussan Ley and a thought provoking address from Professor Andrew Wilson, Chair of the PBAC. The Minister took time to mingle, to listen and engage and better understand the challenges faced by all cancer patients but particularly those with rare tumour types. By staging the event in the seat of Government we focused their attention on the critical issues and opportunities confronting Australians with cancer.

Survivorship: COSA has, after three years, released its final Survivorship Model. Cancer Voices welcomes it, while remaining concerned that health professionals still appear more interested in survivorship “post active treatment”. For many of us that is a very uncertain area, and we prefer ‘survivorship’ and a focus on wellness and ‘quality of life’ from cancer diagnosis through to the end of life.

Cancer Consumers go Conferencing: Cancer Voices has presented posters at four major cancer conferences – Sydney Cancer Conference, NSW Cancer Institute Innovations, RANZCR ASM, and COSA ASM. Focus is on the CIR Program Evaluation report and its significance for consumer involvement in cancer research. We also spoke at two a plenary sessions about hearing the consumer voice and collaboration, as well as acting as panelists. Except for COSA, each conference has requested and met the criteria to use the prestigious new ‘Consumers Included’ logo this year. A poster: [‘Consumers and communities – key partners in biobanking’](#) was also presented at the Australasian Biospecimen Network Association annual conference, and Cancer Voices represented consumers on 3 panel sessions of the inaugural ‘Bowel Cancer Screening Symposium’ held in Adelaide in October.

Lack of written info about prescription medicines: Cancer Voices, together with Consumers Health Forum, is pursuing solutions to address the info gap whereby 70% of Australians health consumers do not receive either package inserts or Consumer Medicines Information CMI (as prescribed by the TGA) with their drugs. Medicines Australia is facilitating a Steering Group, including consumers, to progress the options and make recommendations to government, industry and dispensing pharmacy.

Medical cannabis: Federal legislation has come into effect and the states are now introducing Bills to enable the production and processing of the strains of cannabis known to be efficacious in a number of conditions, including cancer. In the meantime, we support efforts by United in Compassion for the import of appropriate products.

Consumers Included “seal of approval”: This Cancer Voices initiative is continues to attract interest (12 to date) by signalling events demonstrating the active involvement of consumers. Details can be found at <http://www.cancervoicesaustralia.org/consumers-included/> and <http://consumersincluded.wordpress.com/>.



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

