



Cancer Voices Australia NEWS UPDATE

March 2013

Say No to Gene Patents Campaign

Cancer Voices Australia is calling for an Amendment to the Patents Act 1990 which would **clearly exclude the ability to grant patents over any human genetic material**. We have circulated an approved petition to the House of Representatives (download from website) which is already attracting strong support.

The campaign follows CVA's decision to concentrate efforts towards legislative change, for which there is strong public and political support, while keeping in touch with the Appeal being run by Maurice Blackburn. Our response to the negative Federal Court finding of 15 Feb gave CVA valuable media coverage. CVA has visited leading politicians in Canberra (28 March) and Sydney. CVA will:

- continue to circulate CVA's petition and collect signatures for later tabling in the House of Reps.
- continue to take advantage of media opportunities, eg the US Supreme Court decision. The US Government has submitted a strong amicus brief supporting removal of patentability of human genetic material, as have many other leading American researchers
- provide input to a possible draft amendment Bill
- gather a group of prominent Australian researchers who are willing to counter the expected (and unfounded) threats that without patents, research in will cease.

Submissions to National Inquiries

CVA has made formal submissions to the following Inquiries:

- Inquiry into the Compulsory Licensing Provision in the Patents Act 1990, Productivity Commission
- Patient input to PBAC and MSAC Agendas
- McKeon Review into Health & Medical Research
- Review of Pharmaceutical Patents, IP Australia
- Changes to TGA premarket assessment requirements for medical devices
- Submission to the Senate Inquiry re supply of chemotherapy drugs such as Docetaxel

Other action

CVA members have met with major national cancer stakeholders, Ministers and their Offices, contributed to the Flinders Charter of Cancer Survivorship (SA), the Inquiry into Medical Use of Cannabis (NSW), the opening of Gosford Cancer Centre (a CV NSW imitative) and meetings with American cancer consumer advocacy and support organisations. They have been invited to join important national Boards and Committees.

Matching program for consumer reps

CVA's new online facility for responding to stakeholders' requests for informed consumer representatives has taken off. To date we have nominated 9 reps to 7 policy developers, service providers and researchers across Australia. A Consumer Engagement Plan for research groups is being developed in consultation.

Cancer Voices Australia is the independent, 100% volunteer voice of people affected by cancer, working to improve the cancer experience for Australians, their families and friends. We are active in the areas around diagnosis, information, treatment, research, support, care, survivorship and policy. To achieve this we work with decision-makers, ensuring the patient perspective is heard.

Cancer Voices has led the cancer consumer movement in Australia since 2000. Cancer Voices organisations across Australia share the same objectives and work together on national issues identified as important by their members, with consumers working to help others affected by cancer.

What we do: Cancer Voices Australia can provide:

- informed cancer consumer views on national issues;
- representatives to participate on national level decision-making committees; and our "match-making" service to link stakeholders with appropriate consumer representatives