Senator Rachael Siewert Chair Senate Community Affairs References Committee (Gene Patent Inquiry)

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The voice of people affected by cancer

Dear Senator Siewert

Cancer Voices NSW Response to Submission no 76 (Sen Heffernan)

Thankyou for the opportunity to comment on Senator Heffernan's Submission and recommendations. I was surprised that this is a part of the Senate Inquiry process, but having received it, I feel it is very important to respond on behalf of Cancer Voices NSW.

Cancer Voices NSW provides the independent voice of people affected by cancer. It is the peak coalition for cancer support and advocacy groups in NSW, working to improve the cancer experience of the 40,000 people who are diagnosed each year. Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care. To achieve this we work in partnership with providers of these services, ensuring the patient perspective is heard.

As a leading Australian cancer consumer organisation, we wish to strongly support the present opportunity to recommend changes to the Patents Act 1990. We seek amendments to ensure that our medical and scientific research, and concomitant healthcare, is not compromised by the present apparent ability to grant patent monopolies over human genes. We support all of the recommendations put forward by this Submission.

Such amendments would reflect international opinion, most recently expressed in the US Court decision of 29 March, against the patenting by Myriad Genetics of the BrCa 1 and BrCa 2 genes. The reasons for our view have been expressed in our written and oral submissions to the Inquiry. They are also clearly reflected and expanded upon by Senator Heffernan's recent submission, which includes a extremely thorough scrutiny of the evidence put to the Inquiry.

We are pleased to see that the Senator has addressed the arguments and evidence raised by submissions from those with views contrary to ours, of the public interest. These views appear to be held by some patent lawyers who may have a conflict of interest in arguing to preserve the present mis-application of patents to human genes. We suggest that such possible conflicts should be noted in the Inquiry's final report.

We, and the hundreds of thousands of present and future cancer patients, look forward to a favourable outcome for ourselves and for our community.

Yours sincerely

AC hosing

Sally Crossing AM Chair, 9 April 2010

Copy to Ms Naomi Bleeser, Committee Secretary