

## Select Committee into Funding for Research into Cancers with Low Survival Rates - Submission 2017

My name is Christine Jones.

There are three reasons why I am making a submission.

- I have lost several family members and close friends to cancer.
- My husband passed away at home after a number of years suffering from cancer and I was his full-time carer.
- I was employed by the Health Department of Western Australia so I am acquainted with government funding policies and procedures in the health area.

We know that some cancers have low survival rates, and there are several reasons for this. Sometimes it's because some cancers do not have tangible symptoms until late in the disease, making treatment less effective and sometimes impossible. Sometimes it's because the cancer is rare. If a cancer is very rare, it is very difficult to have statistically significant research and clinical trials, and there are very limited numbers of successful treatments. Therefore there is very little on which to build further research, trials and treatments. This cycle continues, leading to low success rates. Low success rates can mean that companies lack incentive to properly fund these cancers, and the cycle continues.

There is very little that can be done about private funding into cancer. Private companies have the right to choose which areas they will fund.

We can, however, effect change in government funding. The current National Health and Medical Research Council funding model favours funding for types of cancer that attract more non-government funding. This is counter-intuitive and goes against government funding policies in other areas. Government funding needs to be spent where there is the greatest need. Certainly we need to be careful with taxpayer money, and factor in the expected return on investment (ROI), but this cannot be the main factor in decision making.

For example, the government provides funds to welfare recipients. Looking at this from a purely financial ROI perspective, the money would be more effectively invested with wealthy stockbrokers, but the government does not and should not do this. Medical funding is the same. A balance must be struck between expected ROI and the health and welfare of Australians suffering from cancer, and their loved ones.

Different types of expenditure will have different returns and effectiveness. For example, public advertising campaigns about rare cancers or cancers which have no known prevention factors will have low return and effectiveness, whereas public advertising campaigns about common cancers and cancers with known prevention factors will have high return and effectiveness. Public advertising campaigns about sun exposure and its effect on skin cancer are examples of public funding used effectively.

On the other hand, funding of actual treatments will have great benefits for patients. In fact it is irrelevant whether the cancer is rare or common; the patients getting treatment will benefit.

Therefore, my first recommendation is that the current National Health and Medical Research Council funding model should be changed. Government funding of treatments should concentrate on those cancers which do not attract non-government funding. This

would provide a more level playing field and would mean that funding would be more fairly shared. This would provide a good chance for improving survival rates for those cancers which currently have low survival rates. It would also improve the current unacceptable situation where one person with cancer has access to affordable medication while another person with a slightly different cancer does not.

My final recommendation is that research on animals not be supported by government funding. It has been proven over many years that animal research does more harm than good. Treatments that don't work on animals have been delayed or discarded, and later found to be effective on humans, and these delays have caused untold unnecessary suffering and deaths. Treatments that do work on animals have been launched on the public and later found to be ineffective or even dangerous. Thalidomide is one of many examples which provided excellent results in animals and devastating tragedy for human beings. Apart from being ineffective, the use of animals in research is not an ethical use of taxpayer money.