Cure Brain Cancer
FOUNDATION
Many minds, one purpose

CURE BRAIN CANCER FOUNDATION: GOVERNMENT SUBMISSION

Pre-budget submission:
Addressing the structural bias restraining brain cancer research

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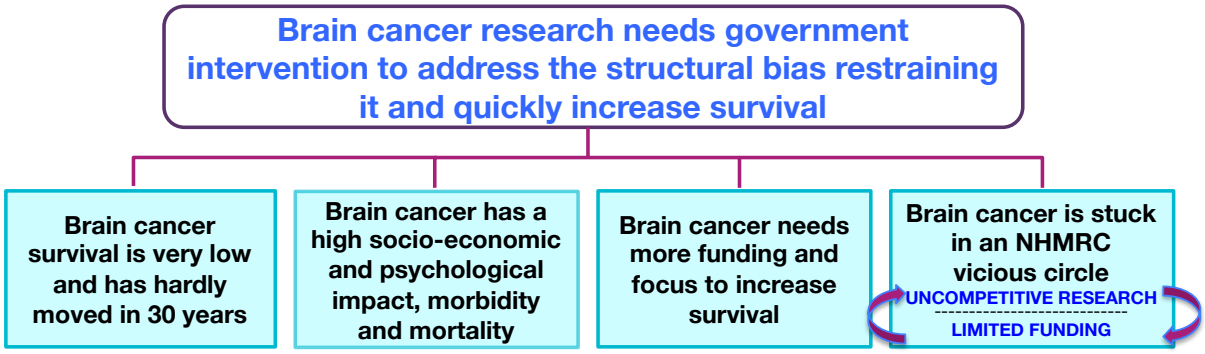
Brain cancer survival has not increased in the last 30 years, even though survival for other (higher incidence) cancers has increased considerably.

Brain cancer kills more children than any other disease and more people under 40 than any other cancer. It is second only to breast cancer as the leading cause of cancer death in women under 40.

It has a high socio-economic impact, costs more per patient than any other cancer, has a high burden of care and often results in people living with brain cancer and their carers being unable to participate in the workforce - yet it receives less than 3% of NMHRC cancer research funding.

While brain cancer research has an increased focus (primarily driven by Cure Brain Cancer Foundation), it is caught in a vicious circle: uncompetitive research results in limited NHMRC funding and limited NHMRC funding results in uncompetitive research.

How can this be circle be broken? How can survival be quickly improved?



There is a clear disconnect between the scope of the problem posed by brain cancer and the resources needed to gain significant traction. We are asking the Australian Government to consider a small intervention to tackle this – the disease that kills more children in Australian than any other.

We urge the Australian Government to earmark funding for a period of time to encourage successful researchers to transition from the highly funded, higher survival cancers to the lower funded, low survival, brain cancer:

1. **Earmark 5% ($5m/year) of NHMRC cancer research funding for 10 years** and, apply an **increased weighting** to brain cancer grant submissions to encourage successful researchers to transition from the highly funded, higher survival cancers.

2. **Providing new sustained funding** to kick-start one or two new laboratories that would be established as a brain cancer **Centre of Excellence**. This would cost $2 million per lab per year over 10 years.

Brain cancer survival is very low and has hardly moved in 30 years

More children die from brain cancer than any other disease ⇨ Brain cancer kills more people under 40 than any other cancer ⇨ Only 2 out of 10 brain cancer patients survive for 5 years

While some children with brain cancer survive for longer than adults, it is well recognised that their quality of life is often terrible as the unwanted effects of radiotherapy and often repeated surgery on the brain - the current mainstays of brain cancer treatment – can be dreadful.

Conversely, thanks to a concerted research effort over the last twenty years, 90% of children with leukaemia now routinely survive for five years with a much better quality of life, as do people with breast cancer.

The fact that brain cancer survival has hardly moved in the last 30 years is sobering. But it also provides a huge opportunity for Australia to invest in world-class research in what is possibly the final frontier of medicine, brain disease. It also offers great opportunities for international collaboration around research and innovation.

Brain cancer has a high socio-economic and psychological impact, with high morbidity and mortality

People living with brain cancer often have low quality of life and high care needs ⇨ The social and psychological impact on families and carers is high ⇨ Brain cancer costs more per patient than any other cancer

In 2012, brain cancer was estimated to account for 21,500 disability adjusted life years (DALYs) in Australia; of these 20,200 were years lost due to premature death and 1,300 were years of healthy life lost due to disease, disability or injury.[i]

Brain cancer costs more per patient than any other cancer because it is highly debilitating, affects people in their prime and often means family members cannot work if they become carers, which many do.[ii]

For those aged 35–44, brain cancer accounted for the highest proportion of cancer expenditure, totalling $32 million. [iii]

The consequences of not dying are nearly as bad as dying as there are few specialised services available. Patients living with brain cancer (and their carers) have high rates of depression and relationship breakdown. The uncertainty of surviving brings very specific challenges and needs even when patients are reasonably well, which many are not. Many become poor, and experience social isolation and stigmatisation.

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Brain cancer needs more funding and focus to increase survival

Government funding and focus for breast cancer and childhood leukaemia research clearly impacted survival
(both now at 90% 5–year survival)

⇨

Brain cancer research is not competitive, receiving less than 3% NHMRC cancer research funding

Over the last 20 years there has been dedicated focus and funding for childhood leukaemia and separately, breast cancer. Both of these are higher incidence cancers, and survival, although good compared with brain cancer, needed to be improved. This has now been achieved and it has been suggested, with their high 5-year survival rates, that both should be now considered as chronic manageable diseases.

The funding focus from Government (and in the case of breast cancer particularly from other additional sources) has resulted in large, quality research programs – these in turn have helped increase survival dramatically. Investment in research clearly improves health outcomes.

Brain cancer is stuck in an NHMRC vicious circle

Brain cancer research needs to attract new talent and increase skills and capacity

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It is very difficult to convince high calibre cancer researchers to shift focus without a clear roadmap of support and opportunity

Over the last 5 years less than 3% of NHMRC grants have been awarded to brain cancer. As a disease with a very poor prognosis, with little improvement in survival or treatments for 30 years, this historically low level of Government funded research activity does not bode well for children and adults living with brain cancer.

A significant number of researchers do submit brain cancer projects as part of the NHMRC process but they are not receiving the scores that are necessary to gain funding. The scores have frequently not been high enough to gain Cancer Australia funding either.

We recognise that the peer-review process at the NHMRC identifies individuals producing high quality research. We are not proposing that the bar be lowered for brain cancer research; instead we look for support to grow the talent pool of brain cancer researchers in Australia.

Without intervention or a shift in NHMRC weightings, it is likely that this ‘vicious circle’ will continue. Brain cancer researchers who do not have a strong track record of research are far less likely to win funding, regardless of community need. With funding being so challenging to secure, researchers tend to apply for funding in areas they see as most likely to be successful through the NHMRC process. As long as weighting of previous research in the field is a

significant consideration, it will be very difficult to convince high calibre cancer researchers to shift their focus to the complex problem of brain cancer.

The solution

Brain cancer research needs government intervention to address the structural bias restraining it and quickly increase survival

1. **Earmark 5% ($5m/year) of NHMRC cancer funding for 10 years** and, apply an **increased weighting** to brain cancer grant submissions to encourage successful researchers to transition from the highly funded, higher survival cancers.

2. **Providing new sustained funding** to kick-start one or two new laboratories that would be established as brain cancer **Centre of Excellence**. This would cost $2 million per lab per year over 10 years.

In a recent conversation with Professor Doug Hilton at the Walter and Eliza Hall Institute he spoke about breast cancer research being in a similar position ten years ago as brain cancer is now. The level of breast cancer research in Australia was fairly average from a global perspective, but due to significant investment in two centres, the quality is now world-class.

Professor Geoff Lindeman heads up the breast cancer laboratory at the Walter and Eliza Hall Institute that was originally funded by the Victorian Breast Cancer Research Consortium, a joint effort between the Victorian Government and various charities. Professor Hilton is strongly in favour of this approach for brain cancer and believes that it would resolve the problems of lack of NHMRC funding.

Cure Brain Cancer Foundation welcomes the significant investment that the Australian and Victorian Governments have made in establishing the world-class Victorian Comprehensive Cancer Centre (VCCC). It may be that the VCCC is the appropriate position for this new initiative. A brain cancer lab focused on clinical trials, coupled with solid laboratory support would be complimentary and will further cement Australia as the Southern Hemisphere's hub for cancer research.

In the context of the Victorian Government's Global Health Melbourne Plan, the Centre of Excellence would attract global attention, drawing international researchers, specialists, investors and patients to what would be the pre-eminent centre for clinical trials and treatment in Asia.

We recognise the need to encourage cross and multi-disciplinary collaboration to encourage innovative thinking in the area. Nanotechnology, immunotherapy, molecular characterisation are some examples of the areas that would have application in brain cancer, as well as breast cancer.

Interestingly, a significant proportion of deaths from breast and lung cancer, melanoma and increasingly prostate cancer (as survival increases) are due to secondaries of these cancers in the brain. These secondary brain cancers share many of the same treatment issues as primary brain cancer as most chemotherapy (and other) drugs do not cross the blood-brain barrier and therefore have limited effect.

By attracting international researchers and developing local talent into brain cancer research, we would expect these researchers to be stronger contenders for competitive funding. The problem is that unless there is sustained investment in this area for a period of time there will be little incentive for serious focus on the disease. While we hope to catalyse this movement as a not-for-profit organisation, the level of funding required to generate impact is beyond our resources. However, an area that we can assist in is to provide proof of concept funding so that brain cancer researchers have additional data to apply for larger NHMRC grants.

We believe that initial support from Government to kick-start the transition of researchers from the highly funded cancers to the lower funded cancers would be a really valuable initiative. We also believe that incentivising top performing early to mid-career stage researchers to choose brain cancer, as a speciality, would have an overall positive impact on health outcomes. Without this incentive, our fear is that our best and brightest will concentrate only where they are likely to receive funding and brain cancer will continue to secure only a small fraction of NHMRC funds. There needs to be a circuit breaker. Brain cancer research needs a 'leg-up'.

Cure Brain Cancer Foundation is the largest dedicated fundraiser for brain cancer research in Australia. Partnering with the research community, we are steering the national agenda for brain cancer research. Our mission is to increase 5-year survival to 50% within 10 years.

Key Objectives

- To fund brain cancer research that offers patients accelerated access to promising new treatments
- To invest into research in excess of $12 million from FY12 to FY15
- To raise awareness of brain cancer
- To support the creation and implementation of a collaborative, international and multi-discipline brain cancer research community

We recognise that to solve a complex problem like brain cancer we need to do things differently; to think laterally and find smarter solutions that allow us to make breakthroughs much faster than traditional research methods allow. We are committed to increasing collaboration across disciplines, teams and borders.

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[i] Australian Institute of Health and Welfare & Australasian Association of Cancer Registries 2012. Cancer in Australia: an overview, 2012. Cancer series no. 74. Cat. No. CAN 70. Canberra: AIHW.
[ii] The Cost of Cancer NSW – report by Access Economics, Australia wide, April 2007.
[iii] AIHW, 2013; Health system expenditure on cancer and other neoplasms in Australia: 2008-09. Cancer series no. 81. Cat. No. 78. Pg 15.