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31 July 2015

Dear Senators,

**Re: Inquiry into the Medical Research Future Fund Bill 2015 and the Medical Research Future Fund (Consequential Amendments) Bill 2015.**

Thank you for the opportunity to make a submission to the Senate Standing Committee on Community Affairs Inquiry into the Medical Research Future Fund Bill 2015. It is with great pleasure that I submit our response, prepared on behalf of CanTeen with the support of eminent and senior health researchers and Youth Cancer Service clinicians, with details shown in Appendix 1.

I would be delighted if we could have the opportunity to appear before the Committee at a public hearing to further elaborate on the issues presented in our submission.

Yours sincerely,

Peter Orchard  
CEO



## CanTeen Response to the Senate Standing Committee on Community Affairs Inquiry into the Medical Research Future Fund Bill 2015

### Executive Summary

CanTeen applauds the establishment of the Medical Research Future Fund (MRFF) by the Australian Government and its flexibility to provide the opportunity to shape investment that will deliver improved health for Australians. It is an extraordinarily important initiative.

However we are extremely concerned that the substantial issues experienced by children, adolescents and young adults (CAYAs) living with cancer will become invisible when a broad 'burden of disease' lens is applied to determine MRFF funding commitments. At the moment CAYAs with cancer are increasingly falling through the gap in terms of access to world class care and our real concern is that this will be amplified in the absence of a targeted approach to manage this risk.

It is for this reason that we are strongly advocating that a priority funding rationale be used to establish a dedicated funding stream within the MRFF for CAYAs, due to the unique conditions of disadvantage and years of life lost through the death and disability associated with how cancer presents in this early and critical stage of life development. Our goal is to ensure that CAYAs diagnosed with cancer have far greater access to early phase, cutting-edge clinical trials and world class research facilities within Australia.

We recommend that this dedicated funding stream for CAYAs be managed through a centralised process in order to establish and foster world class research activities at a national level, including the development of the necessary professional skills. A national approach is necessary to drive the widest possible recruitment of patients, thereby maximising both patient participation and outcomes, although actual on the ground access to trials would need to be de-centralised, to support local access for patients and families.

These funds would also be used to drive co-investment by industry and philanthropic research groups. The outcome of applying this model will be the development of the necessary human and technological infrastructure, as well as cross-institutional collaboration at a national level. Matching funding with partners from the pharmaceutical industry and elsewhere will see the establishment of a more sustainable approach to driving access to world class clinical trials and novel treatment agents.

There is an extraordinary opportunity that comes from focusing on CAYAs, as it is both a group with very high needs and relatively small numbers, resulting in the prospect of key learnings both with respect to the research and the funding model that is applied, and from a comparatively small investment. It is also very important to recognise that the research outputs from this dedicated funding stream will not only be confined to CAYAs, but will have application to older cancer patients as well as those with chronic disease more widely.

An essential component of the CAYA funding stream is that the impact of the research funding is closely evaluated for its impact on mortality, morbidity, knowledge and skills.

The information summarised in our response below outlines:

- The unique challenges experienced by CAYAs living with cancer;
- The system-related barriers impeding the delivery of best practice care to CAYAs; and
- The needs of CAYA cancer survivors throughout the life span.

A brief summary of CanTeen's key achievements in improving the national coordination of oncology services for young patients (15-25 years) is outlined in Appendix 2.

## The unique challenges experienced by CAYAs with cancer

The burden of disease from cancer is high amongst CAYAs, representing the leading cause of death from disease amongst this age group. (1, 2) Amongst adolescents and young adults, is comparable to other significant health burdens such as asthma, cardiovascular and eating disorders and suicide.(3)

CAYA cancer coincides with life's most significant developmental stages, infancy, early childhood and ultimately, transition from childhood to early adulthood. Living with significant and chronic illnesses such as cancer can impact normal development progress in a number of domains. Cancer and late effects of cancer treatment may result in irreversible cognitive and physical complications.(4-7) Consequently, educational and vocational progress may be impaired by school, university or workplace absenteeism; and expectations about academic success may be reduced by attentional and other learning difficulties.(8-10) During the transition to adulthood, aspects of normal psychosocial development such as forming and maintaining romantic relationships(8, 10, 11) and attaining autonomy from one's family(7, 8, 12) may also be substantially delayed.

Cancer-related disruptions to these essential activities can involve significant levels of distress that endure way beyond the completion of active treatment.(13) The impact of cancer also extends to the areas of employment and finances, with survivors of AYA cancers reporting lower levels of paid employment than controls with no history of cancer,(14) and negative impacts upon their financial situation.(15)

With specific reference to adolescents and young adult cancer patients, they experience exceptionally difficult cancer journeys, (16) including significantly poorer survival rates than children and older adults in some of the cancers common in this age group.(1, 17-22) Many of the cancers that affect young people are rare.(23) Young people also present with a larger array of cancer types compared to older adults: 90% of the cancer burden is accounted for by 20 different cancer types.(24) Furthermore, young people also tend to present with cancer at a more advanced stage due to longer delays before diagnosis(25) and suffer higher rates of inferior psychosocial outcomes compared to other age groups.(26, 27) This in turn, is associated with a poorer prognosis and a heightened risk to survival.(28) Consequently, for some cancers, young people show a much poorer response with the same treatments given to older adults or younger children.(29)

## Barriers to the delivery of best practice care for CAYA cancer patients

Access to clinical trials and novel cancer treatments for children with cancer varies from hospital to hospital and jurisdiction to jurisdiction. In addition access to trials for paediatric cancer patients is heavily reliant on philanthropic funding which is estimated to provide for 80% of the cost of undertaking trials in public hospitals. Philanthropy, whilst wonderful for those hospitals that have the support of a philanthropic organisation, is also a significant contributor to inequity of access to clinical trials for paediatric patients.

Within the adult treatment setting, there are barriers to AYA clinical trial participation: up to 95 per cent of young patients, particularly those aged 16+ years, will be treated in an adult hospital where it is highly unlikely that they will have an opportunity to participate in a clinical trial. One Australian study found that 3 per cent of 10-19 year olds and 4 per cent of 20-29 year olds treated in an adult setting participated in a clinical trial versus 38 per cent treated in a paediatric setting.(30)

The low level of clinical trial participation reflects the lack of dedicated trial funding for this age group, coupled with those under 18 not being able to gain access to a trial due to the medico-legal restrictions set by pharmaceutical companies to participants of adult age. Additionally, AYAs often cannot access paediatric collaborative group clinical trials due to their location of care occurring within adult hospitals, preventing their access to these studies due to strict membership requirements. Furthermore, due to the fact that many of the cancers that affect young people are rare, it is difficult to recruit a critical mass of young people sufficient to establish a clinical trials portfolio, resulting in increased costs and further delays in reporting on the outcomes on studies.



The *National Service Delivery Framework for Adolescents and Young Adults with Cancer*(31), developed in 2008, outlines the need for a targeted approach to improvements in service delivery and the development of national quality models of care for adolescent and young adult patients. This Framework is due to be reviewed by CanTeen and Cancer Australia in 2015-16, and will contribute to the development of the evidence base guiding best practice models of care for adolescents and young people.

Given that adolescent and young adult patients are treated in paediatric and adult settings, designing and implementing best-practice models of care that suit both the needs of this age group and are compatible with the treatment setting can be challenging. Specialist care services for adolescent and young adult cancers are not yet commonplace and are not as frequently colocated within the treating hospital as specialist paediatric cancer care.(32, 33)

### **The needs of CAYA cancer survivors throughout the life span**

Subsequent to the completion of treatment, many CAYAs develop serious chronic health problems which have the potential to lower quality of life and result in premature death.(34-36) Long-term follow-up of survivors of CAYA cancer indicates a heightened risk of future malignancy in childhood and young survivors compared to either the general population(37, 38) or survivors of adult-onset cancers (40 years and older).(39) Five-year survivors of CAYA ( $\leq 21$  years) cancers demonstrate a range of cardiac complications at significantly greater rates than their siblings, with the cumulative incidence of adverse cardiac outcomes increasing up to thirty years post-diagnosis.(40) Deficits in physical performance are common among survivors of childhood and adolescent cancers, and appear to have the greatest impact upon survivors of cancers of the CNS, bones and soft tissues, and Hodgkin's disease.(4, 41) Deficits in neuro-cognitive functioning are also well documented for survivors of childhood cancers, especially when treatment was undertaken at a young age.(42, 43)

Amongst adolescents and young adults, psychosocial challenges associated with return to 'normalcy' are also likely to be encountered, as are the many challenges of transitioning from the active-treatment health care services environment to less well coordinated off-treatment settings.(44, 45)

### **The MRFF Bill: implications for planning how to meet the needs of young cancer patients**

CanTeen supports the requirements for the *Australian Medical Research and Innovation Strategy* and *Australian Medical Research and Innovation Priorities*, consisting of criteria outlined in the Supplementary Explanatory Memorandum which included: burden of disease on the Australian community; the delivery of practical benefits to as many Australians as possible; ensuring that the greatest value is provided for all Australians; and ensuring that funding under this Act complements and enhances other funding provided for medical research and medical innovation.

In the context of the cumulative number of CAYA cancer survivors living in the community and the evidence supporting the disproportional disadvantage and ongoing morbidity that this cohort experience, we strongly believe that special consideration for these vulnerable population groups is warranted when setting priorities for the MRFF Bill. CanTeen is extremely concerned that as a heavily impacted group, CAYAs with cancer will not be visible. CAYA populations experience an increased proportion of years of life lost due to premature death and disability when compared with older age groups and require greater attention to address this disadvantage and to ensure that the significance and unique needs of this niche population group is not lost.

There is a clear need to establish a dedicated funding stream to support niche populations like CAYAs living with cancer. Our goal is to enable greater access for CAYAs diagnosed with cancer to world class medical research, including: a clinical trials program and additional investment in research relevant to their complex and critical needs; quality of life studies; psychosocial interventions, including distress and needs



research; and research in health system models, which would ensure a growing evidence base in downstream and upstream factors impacting on best practice patient care. CanTeen, in collaboration with our Research Advisory Group, developed the *Research Priorities for Adolescent and Young Adult Cancer in Australia* report in mid 2014 (46) and a resulting action plan. Key priority areas that were agreed upon included: survivorship; investment in high lethality cancers; building the evidence base through funding AYA targeted research; fertility preservation; and workforce capacity building in research.

A national, dedicated funding stream for CAYAs would need to be managed through a centralised process in order to establish and foster world class research activities at a national level, including the development of the necessary professional skills. A national approach is necessary to drive the widest possible recruitment of patients, thereby maximising both patient participation and outcomes, although actual on the ground access to trials would need to be de-centralised, to support local access for patients and families. Focusing on the development of supportive infrastructure that enables the necessary human, data and technological infrastructure would facilitate data linkage and cross institutional collaboration. For example, identifying the genetic factors which pre-dispose some individuals to cancer is vital, particularly for children and adolescents. Investment in the CAYA age group now with some of the high lethality cancers such as sarcoma will enable early identification, risk stratification and screening to minimise a cancer diagnosis in the future. Investment in biospecimen collection among AYAs, cross-institutional biobanking, data linkage with medical records and health outcomes data for secondary data analysis, with appropriate research access mechanisms would also facilitate access to world class clinical trials, novel treatment agents and its application into treatment pathways. A priority driven approach to funding would maximise the significance of these research outputs on cancer treatment pathways and patient outcomes, and by incorporating a focus on CAYA populations and other niche population groups, the impact of the research outputs could be maximized. Further, given that the delay between health discoveries and the point that they are implemented in a treatment setting has been found to be approximately 17 years,(47) increased investment in translation of findings from discovery research and clinical trials into implementable best-practice models of care that suit the multiple contexts in which AYAs are treated will be vital in ensuring that patients and their families receive maximum benefit with minimum delay.

Administration of this national, coordinated investment would need to be independent of any one jurisdiction or medical entity and ensure strong partnerships to maximise opportunities and share skills and expertise. It is also critical that the research data generated by the funding stream is gathered by the MRFF administration to leverage accountability and data sharing. Another essential component to the CAYA funding stream would be to closely evaluate the longitudinal impact of the research according to mortality, morbidity, knowledge, skills and influence.

CanTeen has a long history of working with key stakeholders such as universities, cancer organisations, Youth Cancer Services and other not for profit organisations to deliver best practice research outcomes (More details of CanTeen's role in this area is provided at Appendix 2). We welcome the opportunity to further discuss a dedicated national funding stream within the framework of the MRFF Bill that can prioritise building clinical research capacity for childhood and AYA cancer research, funding early phase trials and collecting all trial data in the one location.



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## Appendix 1: Youth Cancer Services Governance Groups

In preparing this submission, CanTeen consulted with senior representatives from our Youth Cancer Services (YCS) governance groups, including YCS Leadership Group – Medical team, YCS Research Advisory Group, YCS Strategic Advisory Group and the CanTeen Board. The representatives who provided input on this submission are asterisked (\*) below.

### YCS Leadership Group – Medicos

Dr Michael Osborn*	Dr Lisa Orme
Dr Antoinette Anazodo*	Dr Rachel Hughes
Dr Po-Ling Inglis*	

### YCS Research Advisory Group

Professor David Currow (Chair)	Dr Wayne Nicholls
Dr Antoinette Anazodo*	Dr Michael Osborn*
Dr Cleola Anderiesz	Dr David Thomas*
Professor Afaf Girgis	Dr Tim Threlfall
A/Professor Stephan Jan	Professor Kate White
Professor Bogda Koczwara	

### YCS Strategic Advisory Group

Dr Jenny Bartlett (Chair)*	Professor Ian Olver*
Dr Antoinette Anazodo*	Ms Jenni Seton
Dr Heather Buchan	Ms Kate Thompson
Ms Noelle Cridland	Professor Andrew Wilson
Professor Marion Haas	Mr John de Zwart
Ms Caroline Nehill	



## Appendix 2: CanTeen's track record in improving the national coordination of oncology services for young people

The Australian Government funded the Youth Cancer Network Program (Now the Youth Cancer Service) in 2009 to address the wide variation between jurisdictions in the provision of age appropriate services to young cancer patients within Australia. The initiative was designed to deliver better models of care for adolescents and young adults (15-25 years) diagnosed with cancer and provides a very effective example of how an Australian Government funded program can work in conjunction with other State/Territory health organisations and philanthropic funding sources.

Through this funding CanTeen has established a national network of five Youth Cancer Services, encompassing over 25 major hospitals across every Australian capital city, with the mission to reach every young cancer patient and to provide them with access to specialised, multidisciplinary, youth-specific cancer treatment and facilities. The success of this very important initiative is made possible by the work of many key stakeholders along with CanTeen, including state/territory health departments, COSA, Cancer Australia, Red Kite, the five lead hospital administrators and staff as more recently the Australian Institute of Health and Welfare, South Australian Health and Medical Research Institute and a number of other academic research bodies.

As part of this work, CanTeen has achieved the following:

- A **Strategic Advisory Group** of senior Australian health and cancer specific experts which is chaired by a former Chief Medical Officer of Victoria and includes a former NSW Chief Medical Officer and the recent CEO of Cancer Council of Australia.
- The establishment and **central coordination of a national research agenda**, led by the Research Advisory Committee which is chaired by Professor David Currow (Chief Cancer Officer, NSW) and comprised of highly regarded cancer research experts from every jurisdiction.
- A small portion of CanTeen's funding has focused on **increasing access to clinical research for young patients**. This small scale research funding has limited reach, and to date it has contributed to three major trials (i.e. The establishment of Pharmacokinetics AYAPK clinical trial study; the Acute Lymphoblastic Leukaemia (ALL-06) clinical trial; and the International Sarcoma Kindred genealogy study).
- A **Minimum Dataset for young cancer patients** in partnership with Cancer Australia has been developed and approved. In the next 6-12 months the ethics processes required to address the ethical collection and management of the Minimum Dataset will be undertaken. Over time this patient dataset will become a powerful source of information providing diagnostic, demographic, treatment and health outcome information for young cancer patients.
- A **national network of AYA oncology experts** across all disciplines including clinicians, nursing staff, psychologists and allied health professionals, focused on collaboration, professional development, and skills sharing.
- **Strong international collaborations** and partnerships including the TCT in UK and some cancer charities in the USA.
- **Increasing the integration of workforce** across all states and territories within YCS, including strengthening reach to young people living within rural and regional areas of Australia.



- **Build research capacity in young people and health professionals**, through working in partnership with organisations like ANZCHOG and University of Sydney to run workshops and mentor schemes
- A **national professional development program** for hospital staff that provides multidisciplinary strategic advice to support the development of a comprehensive and sustainable AYA workforce across the YCS services.
- **Seed funding for research.** CanTeen and the Australian and New Zealand Children's Haematology Oncology Group (ANZCHOG) are collaborating by providing joint one-off funding to external organisations for small projects that have the potential to contribute to the development of a clinical trial in the future. In May, three successful research initiatives were announced, with a combined value of \$80,000 (excl GST). These projects have been approved for 12 months starting 1 July 2015:
  - **Breaking the silence around end of life: pilot testing a new advance care planning guide for AYAs with cancer**  
*Lead Investigator: Dr Ursula Sansom-Daly, Kids Cancer Centre, Sydney Children Hospital.*
  - **FUTuRE Fertility psychological health pilot research study**  
*Lead Investigator: Dr Antoinette Anazodo, Kids Cancer Centre, Sydney Children Hospital.*
  - **Circadian and sleep disruption and the impact on quality of life amongst AYA with cancer**  
*Lead Investigator: Dr Robert Battisti, Children's Hospital Westmead.*
- **Undertaken scoping studies** such as the AYA Survivorship Report, through a review of evidence, undertaking key informant interviews, online surveys and holding a focus group of young cancer patients
- **Distress Thermometer validation tool study** to validate the assessment tool used to measure patients' distress at the time of their treatment.