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The Secretary  
Senate Community Affairs References Committee  
Suite s1 59  
Parliament House  
Canberra ACT 2600

Dear Committee Members,

**RE: INQUIRY INTO SERVICES AND TREATMENT OPTIONS FOR PERSONS WITH CANCER**

**Executive Summary**

We write to the Senate Committee asking to be heard on the issue of adolescent cancer care services in NSW. It is our opinion that delivery of cancer care to this group of young Australians is less than optimal and requires urgent attention. Cure rates for adolescents have fallen behind all other age groups. Evidence clearly shows that survival is greatest when adolescent patients are treated in Children's Hospitals. This does not currently happen. Furthermore, psychosocial needs of adolescent patients are unique and poorly addressed with the current model of health care.

Our proposal is that a specialised adolescent cancer facility be established to best meet the needs of adolescent Australians with Cancer. We are proposing a government funded Adolescent Cancer Care Facility initiated by Sydney Children's Hospital and located on the campus of Sydney Children's' Hospital/Prince of Wales Adult Hospital/ Royal Hospital for Women in Randwick, Sydney.

This letter outlines:

- (1) the multiple international studies evaluating disease outcomes for adolescence with cancer which support our proposal; and
- (2) a suggested multidisciplinary model necessary to implement our proposal.

**PROBLEM 1 –ADOLESCENT PATIENTS WITH CANCER HAVE POOR SURVIVAL**

Children and adults with cancer have shown a remarkable improvement in survival and cure rates over the past three decades. However, studies in the U.S. and Europe have consistently shown that the cure rate for adolescents aged 15 to 19 years has fallen drastically behind, with improvements in survival falling at least 50% behind that of other age groups.<sup>1</sup> In addition, it has been shown that adolescents are far less likely to be enrolled on a clinical trial and therefore less likely to receive state-of-the-art treatment.<sup>2</sup> The Australian Health Care service currently provides inadequate services for adolescents with cancer. We are in the process of analysing survival data for adolescents and young adults treated in NSW at either an Adult or a Paediatric hospital. In line with the many other international studies, our results clearly show that survival is poor in patients 15-20 years of age treated in Adult hospitals.

## **PROBLEM 2 – ACCESS TO APPROPRIATE SERVICES**

At present in Australia, there are no guidelines for the referral or appropriate place of treatment for adolescents with cancer. As such, adolescents are randomly referred to either paediatric or adult specialists. The result of this practice has been investigated in significant studies in the U.S.A., France, the Netherlands and Italy. Every study has shown that when adolescents are referred to a paediatric hospital they are far less likely to die than if they are referred to an adult hospital.<sup>3-6</sup> As a result of these findings, many countries around the world are moving to establish specialist Teenage Cancer Units, where the specific medical and psycho-social needs of adolescents with cancer are met. We have included with this submission a short video of an adolescent recently treated at UK Teenage Cancer Trust Facility.

Today in NSW, adolescents with cancer, simple put, fall through the cracks of our current health care system. They are not referred to and treated at paediatric hospitals where it is clear from current evidence they would receive best medical care. However, even the best medical treatment is just one part of optimal cancer care.

## **PROBLEM 3- CRITICAL NEED TO ADRESS PSYCHOSOCIAL NEEDS OF THE ADOLSCENT WITH CANCER**

Psychosocial aspects of care are particularly critical to the adolescent. Adolescence is an emotionally turbulent time at best with many psychosocial issues facing our young Australians including self worth, identity and independence, schooling and workplace pressures, compliance, social experimentation and peer pressure. The needs of the adolescent with cancer are very different from that of a child or adult with cancer. We believe that a Teenage Cancer Care Unit is the only way to deliver appropriate care to this group of Australians with Cancer.

At the Centre for Children's Cancer & Blood Disorders, Sydney Children's Hospital Randwick, we strive to deliver excellence in care to children (under the age of 16) with cancer and their families. We provide this care through a skilled multidisciplinary team that includes physicians, nurses, social workers, play/art therapy, music therapy and school teachers to name a few. This system facilitates a holistic approach to the delivery of cancer care to our patients. Ultimately, this results in best survival and best journey through the treatment process for our patients. In addition, we have consumer advocacy group working closely to help shape and improve delivery of service. We believe this is a necessary model that needs to be directed at delivery of care for all adolescents in Australia with Cancer.

We are committed to delivering an appropriate service to adolescents with cancer and have undertaken several initiatives to address this. First, we are currently in the process of analysing survival statistics for all young patients with cancer in NSW treated in either adult or paediatric institutions. Provisional results show that similar to studies from the USA, UK, Italy and France, survival is superior when adolescents are treated in Paediatric rather than Adult hospitals. Second, we have a committed working party to improve adolescent services in our institution with current goals of developing a cancer handbook written for adolescents as well as hosting an open forum for young people with cancer to discuss all aspects of their care. With both of these initiatives we are working closely with CanTeeN to best service the needs of adolescents with cancer.

## **PROPOSED SOLUTION**

As stated in the opening paragraph, we submit that what is required to address the current crisis in delivery of care for adolescents with cancer is a specialised ward/facility/unit dedicated to Adolescent Cancer Care. This facility will provide an appropriate environment with specialised staff able to address medical and psychosocial needs of the adolescents with cancer. Australian adolescent patients with cancer need and deserve this initiative.

We thank the committee in advance for considering our submission. To progress this important issue, we would be grateful for the opportunity to address the committee in more detail on our proposal.

Yours sincerely,

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