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Mr Robert Coombs MP
Joint Parliamentary Committee on Children and Young People
Parliament of NSW

File Ref: CYP243

RE: Child Death Review Team Report *Trends in Child Deaths in NSW 1996-2005 and* The Child Death Review Team *Annual Report 2007*

Dear Mr Coombs

Thank you for your letter and invitation to the public hearing at Parliament House April 15th 2009 concerning the **Child Death Review Team Report *Trends in Child Deaths in NSW 1996-2005 and the* CDRT *Annual Report 2007.*** I am responding briefly to the three questions in your letter prior to the hearing.

1. The Committee notes that the Standardised Autopsy protocol for Sudden Unexpected Death of an Infant (NSW) or the Australasian SIDS protocol was noted in 41 of the 58 autopsies available at the time of the CDRT's last Annual Report. What if any do you consider to be the impact of the use of the protocol?

The aim of standardising an autopsy is to:

- Ensure the autopsy is thorough and explained causes of death are not missed as this may have an important bearing on counselling of the parents and future children, as well as the resolution of the bereavement process
- Ensure that deaths that are unexplained have adequate and sufficient information for them to be classified as SIDS according to the accepted San Diego definition (to impart a degree of certainty that the death is truly SIDS and not in a "grey area" due to inadequate investigation)
- Assist future prevention and research. Accurate information needs to be available on which to direct targeted prevention

Recent literature (Weber MA et al ADC 2008) would suggest that cause of death at autopsy is significantly improved if a recommended autopsy protocol by paediatric pathologists using a range of ancillary investigations (eg radiology, toxicology, microbiology) is implemented. The

authors found in 546 SUDI cases in the UK in which 37% were explained and 63% unexplained. We need such current 'gold standard' expectations of an optimal autopsy service for SUDI cases.

In March 2006 a trial protocol, the Standardised Autopsy protocol for Sudden Unexpected Death of an Infant (NSW) was introduced at all three forensic units in NSW that manage SUDI's and implemented as policy from August 2008. The evidence so far suggests that the explained deaths have increased over the last 5 years. In 2007, of the 67 SUDI deaths in NSW, 37% were explained and 63% unexplained (see Table 1).

Table 1. Proportion of explained to unexplained SUDI deaths 2003-07 from CDRT Annual Reports

Year	SUDI's	Number unavailable at time of reporting	EXPLAINED DEATHS * n (%)	UNEXPLAINED DEATHS SIDS + Undetermined
2003	43	17	28 (65%)	5 + 10 (35%)
2004	43	9	9 (26%)	13 + 12 (74%)
2005	49	5	7 (16%)	33 + 4 (86%)
2006	54	7	12 (25%)	25 + 10 (75%)
2007	67	4	25 (37%)	35 + 3 (63%)

March 2006 Introduction of Standardised Autopsy protocol for Sudden Unexpected Death of an Infant (NSW)

The increase in explained deaths over the last five years suggests that the autopsy protocol and more complete reporting may have contributed to the increased identification of cause of death. The 2003 figure showing 65% explained deaths is likely spurious as nearly one third, 17 of 60 SUDI (28%) deaths were unavailable for classification.

However a systematic, best practice approach is needed for the whole investigatory process when SUDI occurs as defined previously (Jeffery HE Literature Review for CDRT 2002). Autopsy is only one part of a continuum in a diagnostic process that requires standards for all parts including the history, examination of the death scene, examination at autopsy, ancillary investigations and multidisciplinary case discussion to assign cause of death.

Best practice guidelines for the investigation of SUDI's have been developed in the UK and in the US concerning:

- Collection of information from all relevant sources as soon as possible after death, ideally within 24 to 48 hours, by a trained health professional and police investigators.
- Standards for death scene investigation
- Standards for post-mortem protocols, ideally undertaken by a paediatric pathologist or in conjunction with a designated forensic pathologist.
- Specialised investigations with the conditions that provide optimal yield and include radiology, metabolic and toxicological tests
- Multidisciplinary case discussion to assign the most likely cause of death and contributory factors
- Certification of the cause of death

A recent study (Arnestad M et al Forensic Sci Int 2002) found that review of the circumstances (42%), followed by macroscopic and microscopic (histological) examination (44% and 40%,

respectively) were the three most important autopsy investigations for the detection of identifiable causes of death. In two thirds of the cases more than two investigative components were required at autopsy to determine cause of death.

The protocol released Dec 22nd 2008 NSW Health entitled "Death –Management of SUDI" (PD2008_070) addresses some of this process. However it is yet to be implemented by the systematic education of all stakeholders engaged in the process. Importantly, experience has shown that protocols when developed on best available evidence require auditing to ensure quality and the whole multidisciplinary process managed in order to sustain the needed behavioural change for best practice to occur. This has yet to be achieved for the autopsy protocol and for the management of the more complex SUDI protocol.

2. The CDRT Annual Report 2007 states that the number of infants who died suddenly and unexpectedly in 2007 was the highest in seven years, and substantially higher than for 2006. Do you consider that this was due to the broader definition of SUDI, or were there other factors contributing to this increase?

SUDI numbered 67 in 2007 of which 6 died while 'awake', that is 61 infants died during apparent sleep, the definition used for SUDI in previous years. When recalculated as 61 deaths this resulted in a rate similar to previous years of 66.46 Crude Mortality Rate.

However it is notable that SUDI has not really declined in the last 7 years with 50 to 60 infants dying each year in NSW, and over 90% demonstrating the presence of at least one risk factor, that indicates nearly all these deaths are potentially preventable.

3. The Trend Reports notes that infants living in relatively high socio-economic areas were 44% less likely to die suddenly and unexpectedly than were those living in relatively low socio-economic areas. Can you explain to the committee what factors might contribute to the higher rate among children in low socio-economic areas?

Previous CDRT reports and in particular the analysis in the CDRT research monograph entitled "SUDI the NSW experience " demonstrate a consistently increased risk of SUDI in

- Indigenous infants (six fold)
- Excessive number of preterm infants amongst SUDI deaths (29% in 2007 report compared with a background rate of 7-8%)
- Excessive number of deaths in remote as opposed to urban communities and
- Unsafe sleeping practices that place infants at risk (side or front sleeping, smoking during pregnancy) associated with a lower level of maternal and paternal education which needs to be addressed with appropriate educational strategies.

Each of these risk factors is known to be closely associated with lower socio-economic status. Data from Western Australia indicate that the elevated risk of SUDI in Indigenous infants can be attributed to known risk factors including unsafe sleeping practices, and smoking. The information in the CDRT reports provides evidence on how to target safe sleeping messages for parents and health providers.

I look forward to discussing this further with the committee so that the excessive loss of life of 50 to 60 otherwise healthy normal infants each year in NSW is prevented.

Yours sincerely,

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