# STATE CHILD DEATH REVIEW BOARD


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Testimony in support of SB 77
Written to the Senate Judiciary Committee
By Katherine Melhorn, MD, FAAP
Kansas State Board of Healing Arts appointee to the Kansas Child Death Review Board

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Dear Chairman King,

As a member of the Kansas State Child Death Review Board since its inception in 1992, I am grateful to the legislature for their recognition of the importance of child death review to the health and well-being of our children. Kansas was one of the earlier states to initiate review of all child deaths with the goal of understanding why children die in order to knowledgeably institute prevention measures. Nationally, child fatality review teams were first established to review suspicious child deaths for the purpose of finding missed abuse and neglect cases. Child death review has now expanded toward a public health model of prevention of child fatality through systematic review of child deaths from birth through adolescence. By reviewing all causes of child deaths we are able to develop a powerful tool in understanding epidemiology and preventability of child death locally, regionally and nationally. We are also able to improve the accuracy of vital statistics data collection and identify public health and legislative strategies to reduce preventable child deaths. Both the American Academy of Pediatrics and the American Bar Association have endorsed child death reviews.

Our initial legislative mandate in 1992 allowed us to collect data about each child death in the state and present the de-identified, aggregated information to the legislature in an annual report. Basic statistical analysis of the data helps inform state prevention strategies; for example, looking at how child deaths might be prevented in motor vehicle crashes or drownings, what factors are associated with infant mortality, how children are supervised and cared for in child care settings, what factors increase the risk for Sudden Infant Death Syndrome, gaps in community and medical services and factors associated with child abuse/neglect fatalities, to name a few.

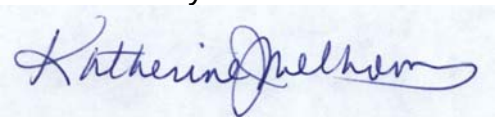
With experience in reviewing the cases and summarizing data from 17 years of child death reviews, our Kansas Child Death Review Board has a wealth of information that could be used to

support sound prevention policies if we were able to share the de-identified case information with appropriate state and national groups addressing these issues. However, the current statutory language does not allow for effective use of our data since we are prohibited from sharing any information we have collected from our reviews, other than what is reported in the annual report. We strongly support the need for confidentiality and protection of personal information regarding each child's death. Every death, preventable or not, is a tragic occurrence for the families involved. Our goal is not to sit in judgment or expose those families to criticism, but we must be able to look closely at how we as a community and state can use the information learned from those tragedies to protect another family from the same outcome.

Any research using case information or shared data would protect the identity of the children or families involved and would be presented or published in an aggregate manner so that no part of the findings would contain personal information. All research is conducted through state institutions such as the Kansas Department of Health and Environment and state universities, all of whom have internal review boards to provide oversight of research and use of data, including human subjects ethics and compliance. Any review of our records or data would be in accordance with rules and regulations adopted by our board, which would also provide oversight of the use of the data to assure confidentiality will be maintained.

By allowing our findings and data to be used for research analysis and by sharing those analyzed findings with state and national agencies and institutions we can strengthen public policy through rational, evidence-based approaches. The American Academy of Pediatrics Committees on Child Abuse and Neglect, and on Injury, Violence, and Poison Prevention, along with liaisons from the Center for Disease Control, Consumer Product Safety Commission, National Highway Traffic Safety Administration and the National Institute of Child Health and Human Development in a policy statement on Child Fatality Review, support comprehensive child death review with the use of data from these reviews to be aggregated, analyzed and disseminated in order to help shape local, state and national policies for reducing child deaths.[1] After developing appropriate interventions to prevent child deaths, having the ability to share the data and research the outcomes of those interventions also allows our Child Death Review Board to evaluate the effectiveness of prevention efforts and modify or improve interventions as needed.

I respectfully request your support of SB 77 and appreciate the opportunity to provide this written testimony.



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1. Policy Statement – Child Fatality Review. *Pediatrics* 2010; 126: 592-596.