Chairman Owens and members of the committee, I am Dr. Sarah Johnston, Clinical Associate Professor of Internal Medicine with the University of Kansas School of Medicine in Wichita and the Commissioner of Education’s appointee on the Kansas State Child Death Review Board (SCDRB). Thank you for the opportunity to speak on Senate Bill 360 which seeks to amend the statutory authority of the SCDRB by incorporating language that will allow the Board to share de-identified information and records for research and public health purposes.

As you may be aware, the SCDRB is a multi-disciplinary, multi-agency board administered by the Office of Attorney General. The SCDRB was created in 1992 for the purpose of reviewing circumstances surrounding the death of every child age birth to 17-years who was a Kansas resident or died in the State of Kansas. Since 1994, the board has reviewed and summarized facts surrounding the deaths of approximately 8,400 children. The SCDRB collects records regarding child deaths, while maintaining confidentiality; they do not have authority to share records or information other than through its highly summarized annual report.

Child deaths are tragic events that are extremely painful for family members, healthcare and law enforcement professionals, school personnel, and society as a whole. Many have asked, “How did this happen when it could have been prevented?” Through the years, legitimate requests have been made to the SCDRB for access to de-identified records and information on child deaths to help answer that exact question. The requests have been routinely denied due to the SCDRB’s existing statutory language which will not allow the sharing of the records and information. Confidentiality is a prime concern for the SCDRB and staff; however, we believe confidentiality can be preserved while providing access to pertinent information.

A copy of the State Child Death Review Board’s 2011 annual report has been provided to each of you. This is the only public work product allowable under the SCDRB’s statutes. It is the opinion of the members of the board, that the current statutory language does not sufficiently allow for the effective use of the board’s data, which could be used to improve the health and well-being of Kansas children.
With the benefit of time, we have seen that the statute falls short of its intended purpose. Thus, I am here today requesting your support for SB 360 which includes an amendment that will allow the SCDRB to disclose de-identified information and records preserved for child death reviews for research and public health in accordance to rules and regulations adopted by the board.

Thank you for the opportunity to appear before the committee today. I will now stand for questions.

Further questions can be directed to Angela Nordhus, Executive Director Angela.nordhus@ksag.org, (785) 296-7970