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## DEPARTMENT OF HEALTH AND ENVIRONMENT

Testimony on Birth Defects Information System, SB 418 to
House Health & Human Services Committee

by Linda Kenney Director, Bureau for Children, Youth and Families Kansas Department of Health and Environment

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The Kansas Department of Health and Environment supports passage of SB 418. We believe that a birth defects registry should be a feature of the Kansas public health system. Birth defects are the leading cause of infant mortality in Kansas and the U.S. In addition, birth defects are the 5th leading cause of years of potential life lost before age 65 and contribute substantially to childhood morbidity and long-term disability. About 30% of all admissions to pediatric hospitals are because of an illness related to a birth defect. Birth defects have a significant economic impact. Costs pale in comparison to the cost of personal anguish for the family and the loss of creativity and productivity of individuals with such conditions.

The etiology of most of these conditions is not yet known, however, where an etiology has been determined, it is often possible to prevent the condition. For example, over 50% of neural tube defects are preventable with the preconception use of vitamin folic acid. Fetal alcohol syndrome may be prevented by abstaining from alcohol during pregnancy. Congenital rubella syndrome is preventable by ensuring immunization of all women. All these interventions are cost-effective.

Birth defects surveillance is a critical component in the effort to reduce the impact of this health problem. It helps to monitor occurrence of birth defects for changes in incidence or for the presence of unusual patterns that may suggest the introduction of new teratogens (agents linked with fetal deformities). It establishes a case registry for use in epidemiologic and genetic studies. In recent years there has been a trend to link program and service needs to surveillance findings. Thus, the system would provide data for health policy decisions and formulation of interventions, and evaluation of the impact of such measures. The system would also identify children who require special services and link them early on with appropriate care providers.

We commend the legislature for recognizing the importance of a birth defects information system to the State's overall public health system. If this legislation passes, KDHE will attempt to identify alternatives to SGF funding for the system and will report any funds to the Committee. Thank you for the opportunity to appear before this committee to support your legislation. I will gladly stand for questions.



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