



Establishing a Birth Defects Information System in Kansas
Testimony on behalf of the March of Dimes
Before the House Committee on Health and Human Services
March 8, 2004

My name is Norm Hess, and I am the Director of Program Services for the March of Dimes Greater Kansas Chapter. Thank you for the opportunity to express our strong support of Senate Bill 418, to authorize the establishment of a statewide birth defects information system.

Based on national estimates by the Centers for Disease Control and Prevention (CDC), 1,200 - 1,500 babies were born in Kansas with a major birth defect in the year 2000. The CDC estimates that at least 20% - more than 50 babies - died in Kansas that year because of birth defects. Some of these conditions are diagnosable at birth and are recorded on the birth certificate. Others may not manifest symptoms for several months and may never be reported to the Kansas Department of Health and Environment (KDHE) under the current reporting system.

According to the CDC, Kansas is one of only 4 states that do not have an active reporting birth defects information system. Currently, 35 states receive funding through cooperative agreements from the CDC to plan and implement birth defects information systems. These agreements have resulted in more timely and accurate birth defects data and have led to stronger, more coordinated systems of care for children and families.

CDC funding for the purposes of establishing or enhancing state birth defects information systems is expected to continue. Passage of authorizing legislation at this time will strengthen the state's position in applying for these funds.

The reporting of health-related information to the state health authority is a long-standing public health practice, and KDHE routinely collects, stores, and processes confidential health information. SB 418 contains appropriate measures to protect the confidentiality of children and families, including a provision for parents or guardians to have identifying information about their children removed from the system.

The March of Dimes strongly supports SB 418 to benefit the families of children who are born with major birth defects in Kansas each year. Thank you for your consideration of this bill.

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