



TO: House Health and Human Services Committee

FROM: Christina Collins
Director of Government Affairs

DATE: March 8, 2004

RE: Proposed amendment to SB 418 which creates a Birth Defect Registry

Chairman Morrison and Members of the Committee:

Thank you for considering my testimony before the committee today. Please accept my apology for not providing this information prior to the hearing; the attached amendment results from discussions about the bill that transpired just this morning.

The Kansas Medical Society favors the implementation of registries that allow KDHE to gather meaningful data on birth defects in Kansas and to disseminate helpful information to parents of these children.

However, this registry differs from others this body has considered in that it grants KDHE authority to request relevant medical records. The bill's current language does make the records confidential; however, the Kansas Medical Society seeks additional protections for these records that would not otherwise be in the custody of the Kansas Department of Health and Environment to ensure that they cannot be subsequently released by KDHE. While it is helpful for KDHE to access this information, these records contain confidential medical information of a highly sensitive nature. For this reason, the interested parties, including the March of Dimes and KDHE have approved the addition of the attached amendment to the bill's current language.

The proposed language is almost identical to that adopted by the Senate Judiciary Committee and the Senate as a whole to SB 466, which creates protections for medical records a physician may provide to the Division of Motor Vehicles to substantiate a report that a patient lacks the capacity to drive safely. Again, parties who may need access to these records have adequate alternative means to secure them but the highly personal nature of the records merits their continued protection after these records leave the control of the health care professional or the patient themselves.

Again, we support the goal of creating a birth defect registry but feel these protections are important to safeguard the privacy and dignity of the children who suffer from these tragic conditions. I am pleased to respond to any questions the committee may have and can be reached by email at ccollins@kmsonline.org or by phone at 235.2383. Thank you for considering my comments.