

SB 230 -- CHLOE'S LAW

SPONSOR: Brown (Brattin)

COMMITTEE ACTION: Voted "Do Pass" by the Committee on Health Care Policy by a vote of 9 to 0.

This bill establishes Chloe's Law that requires, effective January 1, 2014, the Department of Health and Senior Services to expand the newborn screening requirements to include a screening for critical congenital heart disease (CCHD) using a test approved by the department in accordance with the American Academy of Pediatrics and American Heart Association guidelines prior to the newborn being discharged from a health care facility. If a newborn is delivered at a place other than a health care facility, the physician or person professionally undertaking the pediatric care of the newborn must ensure that the screening is performed.

The screening results must be reported to the parents or guardian of the newborn and the department. Health care facilities must develop and implement plans to ensure newborns with positive screens receive appropriate confirmatory procedures and referral for treatment as indicated.

The provisions of the bill must not apply if the parents of the newborn object to the testing due to a conflict with their religious tenets and practices. The refusal of the testing must be in writing and must be made part of the newborn's medical record. Any refusal must also be reported to the department.

Prior to administering the screening, the facility, physician, or person professionally undertaking the pediatric care of the newborn must provide the parents or guardian of the newborn with a written packet of educational information developed and supplied by the department that describes the screening, how it is conducted, available options for confirmatory procedures and treatment, the nature of the disease, and the possible consequences of treatment and non treatment for the disease.

The department must provide consultation and administrative technical support to facilities and persons implementing the provisions of the bill, including assistance in developing and implementing screening protocols; developing and training for facilities and persons on implementing the protocols; developing and distributing education materials for families; and implementing reporting requirements.

PROPOSERS: Supporters say that heart defects are the number one birth defect in the entire world and the number one cause of death

of infants in the United States. Screening for critical congenital heart disease is an easy, inexpensive, non-invasive way to save lives through early diagnosis of very treatable heart defects. All hospitals already have the equipment necessary to test for the disease and the equipment is available in portable sizes for midwives. There are currently 22 other states working on similar legislation and 17 other states have passed similar laws.

Testifying for the bill were Senator Lamping; Kelly Manz; March of Dimes, Greater Missouri Chapter; American Heart Association; Department of Health and Senior Services; St. Louis Children's Hospital; and Missouri State Medical Association.

OPPONENTS: There was no opposition voiced to the committee.