CHAPTER 31

(SB 31)

AN ACT related to newborn screening.

Be it enacted by the General Assembly of the Commonwealth of Kentucky:

Section 1. KRS 214.155 is amended to read as follows:

(1) The administrative officer or other person in charge of each institution caring for infants twenty-eight (28) days or less of age and the person required in pursuance of the provisions of KRS 213.046 shall register the birth of a child, and cause to have administered to every such infant or child in its or his care tests for ***heritable disorders***~~[inborn errors of metabolism]~~, including but not limited to phenylketonuria (PKU), ***sickle cell disease, congenital hypothyroidism, and galactosemia*** in accordance with rules or regulations prescribed by the secretary of the Cabinet for Health Services. Testing, recording, and reporting of the results of ***newborn screening***~~[such]~~ tests shall be performed at ***the***~~[such]~~ times and in ***the***~~[such]~~ manner as may be prescribed by the secretary of the Cabinet for Health Services or ***the secretary's***~~[his]~~ designee. The secretary of the Cabinet for Health Services shall by regulation establish and collect fees to cover the cost of analyzing the testing samples for ***newborn screening tests***~~[inborn errors of metabolism]~~.

(2) Nothing in this section shall be construed to require the testing of any child whose parents are members of a nationally recognized and established church or religious denomination, the teachings of which are opposed to medical tests, and who object in writing to the testing of ***his or her***~~[such]~~ child on that ground.

(3) The cabinet shall make available the names and addresses of health care providers, including, but not limited to, physicians, nurses, and nutritionists, who may provide postpartum home visits to any family whose infant or child has tested positive for ***a newborn screening test***~~[an inborn error of metabolism, including, but not limited to , PKU]~~.

(4) Contingent upon the receipt of federal grants or appropriations by the General Assembly of the Commonwealth of Kentucky, the tests for heritable disorders for newborns listed in subsection (1) of Section 1 of this Act shall be expanded to include, but not be limited to, medium-chain acyl-CoA dehydrogenase deficiency (MCAD), very long-chain acyl-CoA deficiency (VLCAD), short-chain acyl-CoA dehydrogenase deficiency (SCAD), maple syrup urine disease, congenital adrenal hyperplsia, biotinidase disorder, and cystic fibrosis.

(5) The secretary for health services or his or her designee shall apply for any federal grants available through the Public Health Service Act to expand or improve programs to provide screening, counseling, testing, or specialty services for newborns or children at risk for heritable disorders.

(6) The secretary for health services or his or her designee shall apply for any federal grants available through the Public Health Service Act to evaluate the effectiveness of newborn screening, counseling, or health care services in reducing the morbidity and mortality caused by heritable disorders in newborns and children.

Approved March 15, 2001