

SESSION OF 2022

SUPPLEMENTAL NOTE ON SENATE BILL NO. 155

As Recommended by Senate Committee on
Public Health and Welfare

Brief*

SB 155 would update statutes related to newborn screening and designate those statutes as the Newborn Screening Act (Act). The bill would also establish the Universal Newborn Screening Program (UNSP) within the Act.

The bill also would make technical changes.

***Newborn Screening Act – Amendments; Program
Creation***

The bill would update provisions related to the Act to:

- Establish the UNSP to be administered by the Secretary of Health and Environment (Secretary);
- Remove the list of conditions included in the Act and grant the Secretary the authority to determine the conditions to be included in the UNSP. The bill would require the Secretary determine the conditions included in the UNSP, including, but not limited to, conditions listed in the recommended uniform screening panel recommended by the U.S. Secretary of Health and Human Services;
- Clarify the stated purpose for maintaining a registry of cases to specify the registry will maintain information of importance including follow-up to

*Supplemental notes are prepared by the Legislative Research Department and do not express legislative intent. The supplemental note and fiscal note for this bill may be accessed on the Internet at <http://www.kslegislature.org>

support early diagnosis, treatment and services for healthy development, or the prevention of disability or morbidity;

- Remove guidelines for the reimbursement and purchase of medically necessary food treatment products for all purchasers, including the Kansas Department of Health and Environment (KDHE), and add language that purchasers will be reimbursed in accordance with rules and regulations adopted by the Secretary; and
- Increase the amount available for transfer from the Medical Assistance Fee Fund to the Kansas Newborn Screening Fund from a maximum of \$2.5 million to a maximum of \$5.0 million in any one fiscal year.

The bill would be in effect upon publication in the *Kansas Register*.

Background

The bill was introduced by the Senate Committee on Ways and Means and referred to the Senate Committee on Public Health and Welfare.

[*Note:* HB 2250, which contains similar provisions, has been introduced in the House.]

Senate Committee on Public Health and Welfare

In the Senate Committee hearing, representatives of Kansas Action for Children, KDHE, and The Treehouse and four private citizens provided **proponent** testimony, stating the screening program allows for identification of many conditions that can be successfully treated through early intervention, which can be life-changing for children and their families. Proponents stated additional funds would help ensure the program continues to have adequate support.

Written-only proponent testimony was provided by representatives of the American Academy of Pediatrics, Kansas Chapter; Kansas Children's Cabinet and Trust Fund; Kansas Commission for the Deaf and Hard of Hearing; Kansas Hospital Association, Kansas Newborn Screening Advisory Council; Kansas School for the Deaf; and a private citizen.

No other testimony was provided.

Fiscal Information

According to the fiscal note prepared by the Department of the Budget on the bill, KDHE indicates the bill would provide for growth and expansion of the newborn screening program. Under the current maximum transfer of \$2.5 million to the Kansas Newborn Screening Fund, the Department allocates approximately \$550,000 to Newborn Screening Follow-Up and \$1.95 million to testing performed by KDHE laboratories. KDHE indicates that increasing the transfer to a maximum of \$5.0 million would allow the agency to allocate \$1.065 million for Newborn Screening Follow-Up, \$3.45 million to testing performed by KDHE laboratories, and \$485,000 to Newborn Screening Systems of Care. However, KDHE notes that under current law, transfers to the Kansas Newborn Screening Fund are based on actual expenditures and increasing the transfer limit would not result in immediate increases to expenditures equal to the new cap. Reaching the allocations above would occur over time.

Currently, most of the Medical Assistance Fee Fund is used for KDHE KanCare expenditures under the Human Services Consensus Caseloads process. Increasing the transfer to the Kansas Newborn Screening Fund could require an increase of up to \$2.5 million from the State General Fund for caseloads. Any fiscal effect associated with the bill is not reflected in *The FY 2022 Governor's Budget Report*.

Newborn Screening Act; Department of Health and Environment; screening; rules and regulations