Description
House File 2539 relates to health screenings performed on newborns born in Iowa to discover congenital or inherited disorders. The Bill first codifies the Congenital and Inherited Disorders Advisory Committee (CIDAC) currently established in 641 IAC 4.1. The Bill requires that all conditions currently included in the federal recommended uniform screening panel (RUSP) be included in newborn screenings in Iowa, and that within 12 months of an addition of a condition to the RUSP, the CIDAC must review the addition and make a recommendation to the Iowa Department of Public Health (DPH) regarding the inclusion of the new condition in Iowa’s newborn screening panel. If the CIDAC recommends inclusion of the new condition, the DPH is then directed to ensure that the new condition is included in the State’s screening panel within 18 months of receiving the recommendation. The Bill also requires the DPH to submit an annual report to the General Assembly by December 31 regarding current conditions included in the State’s screening panel, any new conditions currently under consideration or recommendation by the CIDAC, and any conditions considered that did not receive a recommendation to be included with the reason for not being included. House File 2539 also directs the State Hygienic Laboratory (SHL) to establish the newborn screening fee schedule to support the costs of the program.

Background
There are currently 35 congenital and inherited disorders included on the RUSP, 32 of which are currently being tested for in the Iowa newborn screening. The three disorders included on the RUSP that are not currently being screened for in Iowa are Pompe disease, Mucopolysaccharidosis type 1 (MPS-1), and X-linked adrenoleukodystrophy (X-ALD).

Parents of newborns are currently charged a fee of $122 to cover the costs of the screening tests unless they decline to have their child tested. This fee has not increased in the past seven years.

Assumptions
In order for the SHL to be able to test for the three conditions in the RUSP that are not currently being tested for, the SHL will need additional testing equipment, test development and validation, training, information technology changes, and quality management system adjustments.

Fiscal Impact
The SHL reports that initial startup costs for the three additional tests would be approximately $2.1 million. Operating costs to continue administering the three additional tests are estimated to be approximately $714,000 per year. Increasing the annual operating costs of the newborn screenings would result in a $19.80 increase to the newborn screening fee, which would raise the fee from $122 to $141.80.
Sources
Department of Public Health
Board of Regents
LSA calculations

/s/ Holly M. Lyons
March 8, 2022

The fiscal note for this Bill was prepared pursuant to Joint Rule 17 and the Iowa Code. Data used in developing this fiscal note is available from the Fiscal Services Division of the Legislative Services Agency upon request.

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