Fiscal Estimate - 2021 Session

☐ Original ☐ Updated	Corrected Suppler	nental				
LRB Number 21-1939/1	Introduction Number SB-194	1				
Description newborn screening for Krabbe disease and requiring evaluation of additional lysosomal storage disorders for mandatory screening						
Fiscal Effect						
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Agency/Prepared By	Authorized Signature	Date				
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Fiscal Estimate Narratives DHS 4/15/2021

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Description						
newborn screening for Krabbe disease and requiring evaluation of additional lysosomal storage disorders for						
mandatory screening						

Assumptions Used in Arriving at Fiscal Estimate

Under current law, the attending physician or nurse-midwife must ensure that every newborn undergoes testing for certain congenital and metabolic disorders prior to the infant's discharge from the hospital or maternity home, or within a week from birth for infants born elsewhere. DHS Administrative Code specifies the congenital and metabolic disorders for which newborn infants are screened, with the current Newborn Screening Program screening for 49 conditions including hearing loss.

The proposed bill specifies that, every infant born undergo testing for globoid cell leukodystrophy, also known as Krabbe disease.

The cost for adding on lysosomal storage diseases (LSDs) is \$11 per infant for up to three disorders. With an approximate 61,000 births in 2020, the annual total is \$671,000, which covers instruments, reagents and consumables, and laboratory staff time for the following: testing, result review and reporting, and program follow up activities on screening positive cases.

Currently, the Secretary's Advisory Committee on Newborn Screening has recommended to add Pompe disease, another LSD, to the newborn screening panel. The Department will need to implement an administrative rule change to add the disease. Should Pompe disease be added to the screening panel, Krabbe disease could be added at no additional costs since it would fall under the costs to add up to three disorders to the screening panel. However, should Pompe disease not be added to the newborn screen it would cost \$671,000 per year to add Krabbe disease to the newborn screening panel.

In summary, it is estimated that the bill will increase costs to WSLH by \$671,000 PR per year, resulting in a revenue shortfall of an equal amount in DHS.

Long-Range Fiscal Implications