AN ACT TO AMEND TITLE 16 OF THE DELAWARE CODE RELATING TO THE NEWBORN GENETIC TESTING PANEL

Legislative Request

This Act requires that the Delaware Department of Health and Social Services establish a public, biannual process to revise the state's newborn genetic testing panel in accordance to the federally promulgated recommended uniform screening panels.

Executive Summary

Newborn screening can identify serious metabolic disorders before symptoms appear, when early diagnosis and treatment may prevent severe medical complications and death. Delaware's Newborn Screening Program currently screens newborns for a range of rare disorders, but the current panel is not aligned to the FDA's RUSP (recommended uniform screening panel). This Act establishes a regular, public process for reviewing the panel against the RUSP within six months of updates to the panel. Conditions deemed unfit for addition to the state's newborn testing program shall be reevaluated annually by a committee of healthcare professionals in consultation with the Department of Health and Human Services.

Rationale

Newborn screening should keep pace with new treatments, testing methods, and medical evidence. The federal RUSP is updated as evidence supports adding new conditions, but Delaware's current screening panel does not align with it at this time. A regular public review would allow Delaware to consider new RUSP recommendations on a timely basis and hear from health professionals and affected families. This process would help Delaware keep its screening panel up to date and reduce delays in considering new conditions.

Proposed Action

This bill establishes a transparent, public review process for Delaware's newborn screening panel, requiring the state to evaluate all conditions on the federal Recommended Uniform Screening Panel (RUSP) and consider newly added conditions within six months. It also requires periodic reevaluation, public input, and published reports explaining decisions to exclude recommended conditions, ensuring greater accountability and alignment with federal screening recommendations.

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