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 through a committee of five licensed health professionals.

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 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

The DHSS will establish a five member committee of health professionals to publicly review disorders for the state's newborn genetic testing panel including, but not limited to, those included in the federally promulgated recommended uniform screening panel.

Contact

Alek Lee & Manav Suresh
Founders, Delaware Youth Rare Disease Initiative
Email: delaware.yrdi@gmail.com
Cell: 302-824-8932