



Committee: House Health and Government Operations Committee
Bill Number: House Bill 109
Title: Maryland Department of Health – System for Newborn Screening – Requirements
Hearing Date: January 19, 2022
Position: Support

The Maryland Affiliate of the American College of Nurse Midwives (ACNM) supports *House Bill 109 – Maryland Department of Health – System for Newborn Screening – Requirements*. This legislation will ensure that Maryland’s Newborn Screening Program is kept up-to-date by requiring that disorders recommended by the U.S. Department of Health and Human Services (HHS) are added to the State screening panel within two years.

When considering adding a new disorder to HHS’s Recommended Uniform Screening Panel (RUSP), an expert panel reviews the available research to determine the presence of “evidence that supports the potential net benefit of screening, the ability of states to screen for the disorder, and the availability of effective treatments.” Among a variety of factors that are considered are the requirement that the disorder under consideration can be identified before a child becomes symptomatic and the presence of available treatment to prevent the child from ever becoming symptomatic. These are important criteria because disorders on the RUSP have significant impacts on the health and lives of children who have them and are often very expensive to treat after a child becomes symptomatic.

Currently, Maryland tests for 34 of the 35 federally recommended disorders. Maryland is not testing for X-linked adrenoleukodystrophy (X-linked ALD), a genetic disorder that mainly affects the nervous system and the adrenal glands.ⁱ Left untreated, this disorder reduces the ability of nerves to relay information to the brain. Additionally, damage to the adrenal glands may result in weakness, weight loss, skin changes, vomiting, or coma.ⁱⁱ In its most severe form, X-linked ALD can result in death during childhood or adolescence.ⁱⁱⁱ Although HHS recommended screening for X-linked ALD in 2015, Maryland is still not testing for it, making it more difficult to connect children to life saving treatment.

ACNM supports this bill because it ensures that Maryland children receive newborn screening in accordance with federal recommendations. Thus, families will be able to access life-saving treatment for their children as soon as possible. Thank you for your consideration of our testimony. If you need any additional information, please contact Scott Tiffin at stiffin@policypartners.net or (443) 350-1325.

ⁱ <https://medlineplus.gov/genetics/condition/x-linked-adrenoleukodystrophy/>

ⁱⁱ Ibid

ⁱⁱⁱ Ibid