

LC 460: Updating Newborn Bloodspot Screening

Several statutory changes to Oregon’s Newborn Bloodspot Screening (NBS) program would better serve newborns and their families, including by preventing costs being improperly imposed on families and by ensuring families and their health care providers receive all the information they need to best address congenital conditions experienced by their newborn.

Screening Helps Newborns Be Healthier, But the Process Could Be Better

The Oregon Newborn Bloodspot Screening (NBS) Program is a statewide service that offers screening for all babies born in Oregon to identify congenital health conditions. By identifying potential life-changing – or even life-threatening – conditions within the first week of life, families and their doctors gain the information they need to make decisions to provide their newborns with the healthiest possible future.

The Newborn Bloodspot Screening Advisory Board has identified several concerns about how newborn screening is conducted in Oregon. These include:

- State law declares that no infant will be refused screening because of a family’s inability to pay. However, some health plan providers instruct families to purchase the kits used for newborn screening, and then inconsistently reimburse for the cost, which can indirectly create a financial barrier for families.
- Newborn screening is voluntary. However, current statute only specifies that families may have religious reasons to decline newborn screening. This criterion does not address other reasons why families may decline.
- When initial screening identifies a congenital condition, the newborn receives additional testing to confirm or exclude the screening results. However, often OHA does not receive information on the results of the confirmatory tests from the health care provider. Such reporting would provide the data necessary to monitor testing, improve accuracy, and minimize false positives.

- Occasionally, the screening misses a congenital condition (a “false negative”). When this occurs, and later a health care provider diagnoses the newborn correctly, the provider is not required to report the case to OHA. When this happens, the opportunity to update and improve the screening methods – and ensure all children with a congenital condition are identified – is lost.
- The newborn screen program does not include a general educational component, which could inform parents, providers, and the general public about the purpose and benefits of screening.

Statutory Changes for Better Screening

To address these concerns, the Newborn Bloodspot Screening Advisory Board endorses revisions to ORS 433.285 through 433.295 to:

- Require Coordinated Care Organizations and health insurance companies to cover the cost of newborn bloodspot screening regardless of the provider or delivery option selected by the family.
- Permit a parent or guardian to decline newborn screening for any reason, not limited to religious reasons.
- Require providers to report confirmatory test results and medical outcomes to OHA about newborns who screen positive for a condition.
- Require health care providers to report to OHA about any conditions not detected by newborn screening, but later discovered through other means.
- Authorize OHA to conduct an education program for health care providers and families.

For more information:

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