

# LC 444: Revise Newborn Bloodspot Screening Statutes

## **The Newborn Bloodspot Screening program helps babies live healthier lives**

The Oregon Newborn Bloodspot Screening (NBS) Program is a statewide public health program that provides early health screening within the first week of life for all Oregonians. It identifies medical conditions in infants that require early treatment to prevent death or disability, to improve lifelong health.

Within the first day of life, a health care provider collects a small blood sample from the newborn's heel and sends it to a laboratory for testing. The results are sent back to providers who consult with parents and, if necessary, conduct diagnostic testing and initiate life-saving treatments. NBS is statutorily mandated in Oregon and over 95% of babies in Oregon receive this testing.

In recent year, some inequities related to the program have been identified:

- ▶ Some providers instruct parents to purchase screening kits directly from the Oregon State Public Health Laboratory (OSPHL). OHA has learned that parents or guardians are inconsistently reimbursed by health plan providers in these cases, meaning that families are paying out of pocket for screening costs that should be covered by insurance or waived.
- ▶ Abnormal results from newborn screening require additional follow-up care and diagnostic testing through other medical providers and laboratories. Current statute does not require other medical providers and laboratories to report diagnostic results and clinical outcomes. Because of this, there may be a delay in receiving a correct medical diagnosis, treatment, and social services that support babies and families.

## **The Newborn Bloodspot Screening statutes need revision to reflect modern practices and address inequities**

This legislative concept aligns the NBS statute with modern laboratory and screening practices, some which are already in practice, and addresses current inequities.

- ▶ Requires Coordinated Care Organizations and health carriers (such as insurance companies) to cover the cost of newborn bloodspot screening regardless of the provider or delivery option selected by the expectant parents, to ensure families are not paying out of pocket for this mandated public health program.
- ▶ Requires the NBS Program to implement an educational program for health care providers, expectant parents, parents of infants, and the general public. The aim is to provide information on medical conditions for which infants are screened under the NBS

Program and on the importance of newborn bloodspot screening to prevent or mitigate the harmful health effects of medical conditions for which infants are screened.

- ▶ Clarifies the authority to permit waiver of fees for a parent or guardian, by authorizing the NBS Program to define the specific criteria for fee waiver in rule, thereby providing a stronger community voice in the process of establishing these criteria.
- ▶ Requires medical providers and laboratories to report to OHA confirmed medical conditions detected by the NBS Program, enabling the program to assess its effectiveness at serving families in Oregon.

**For more information:**

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