MARCH OF DIMES

ARIZONA

NEWBORN SCREENING

# NEWBORN SCREENING SAVES LIVES SUPPORT SENATE BILL _____

Newborn Screening isn't just a test. It's an interconnected public health system that relies on the coordinated activities of health care providers, laboratories, public health professionals, and parents. The system includes six critical components:

- Screening for congenital conditions
- Rapid follow-up and referral for infants with positive test results
- Confirmatory testing and diagnosis
- Implementation of treatments and therapies for diagnosed infants
- Education for all stakeholders
- Evaluation of the success of the system

## Background

- Arizona currently tests for **31** of the **35** recommended disorders on the Recommended Uniform Screening Panel (RUSP),
  Arizona does not test for:
  - Spinal muscular atrophy (SMA)
  - Pompe disease
  - X-linked adrenoleukodystrophy (X-ALD)
  - Mucopolysaccaridosis, type 1 (MPS1)

- The Department of Health Services (DHS), who manages the newborn screening program, charges fees for the newborn screening tests. The fee for the first test is set in statute at $36 and is billed to the hospital (typically included in the birth package). The fee for the second test is set in DHS rule at $65 and is billed to the child's health insurance provider or parents. However, the current fees do not cover complete costs to run the program, which include running the tests, equipment maintenance and replacement, and staffing to follow up on positive tests.

- In Arizona, newborns are screened twice – once before they leave the hospital and once at the first well-baby visit.

## Key Bill Provisions

- Bill combines the two screening fees into one fee in statute in the amount of $113. This will cover the current costs of the first test ($36) and second test ($65) and the cost to add two new tests to the panel.

- It will enable DHS to add two of the RUSP disorders for which Arizona is not currently screening, X-ALD and SMA.

## Screening Facts

- Newborn Screening reaches almost all of the 4 million babies born in the U.S. each year.

- Approximately 1 in every 300 newborns has a condition that can be detected through screening.

- Newborn screening is the practice of testing every newborn for certain genetic, metabolic, hormonal and functional conditions that are not otherwise apparent at birth.

- Screening detects conditions that, if left untreated, can cause disabilities, developmental delays, illnesses or even death. If diagnosed early, many of these disorders can be managed successfully.

**CONTACT** Breann Westmore
**EMAIL** bwestmore@marchofdimes.org
**PHONE** (602) 541-9511

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