



# NEWBORN SCREENING



Thanks to Federal Support, Newborn Screening Saves Lives!

## What is Newborn Screening?

**Newborn screening (NBS)** identifies thousands of babies with a rare disease every year. NBS consists of three tests: 1) hearing test, 2) pulse oximetry to check for heart conditions, and 3) a blood test (heel prick) to check for dozens of metabolic, endocrine, hemoglobin, and other disorders, the majority of which are genetic. Nearly all of the 3.6 million babies born in the US each year are screened to detect diseases that require early intervention and treatment to prevent irreversible harm or death.

Each state and territory runs their own newborn screening program but relies on federal guidance and support. All states screen for at least 32 of the 38 conditions on the federal Recommended Uniform Screening Panel (RUSP).

## HOW DOES THE FEDERAL GOVERNMENT SUPPORT NEWBORN SCREENING?

### Health Resources & Services Administration (HRSA)

Through its Newborn Screening for Heritable Disorders program, provides grants and programmatic support for state newborn screening programs to:

- Train professionals in newborn screening and providing counseling to families.
- Provide appropriate follow-up care for children with conditions identified via newborn screening.

Until recently, supported the Federal Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC)\*, which advised the HHS Secretary on:

- Appropriate application of newborn screening tests, technologies, policies, guidelines, and standards.
- Evidence-based recommendations on which conditions should be added to the federal RUSP, a list that currently consists of 38 core conditions and 26 secondary conditions.

\*In April 2025, the ACHDNC was terminated by the HHS Secretary leaving newborn screening programs in the dark about the future of critical guidance and recommendations.

### Centers for Disease Control & Prevention (CDC)

Through its Newborn Screening Quality Assurance Program (NSQAP):

- Supports quality assurance for laboratories and screening tools involved in newborn screening.
- Assists newborn screening programs with implementation of screening for new conditions, improving screening test performance, and training on new technologies.
- Provides a national data platform to improve quality and interpretation of newborn screening results.

### National Institutes of Health (NIH)

Through many NIH Institutes, but primarily the National Institute of Child Health and Human Development (NICHD), funds research to:

- Develop evidence to understand which diseases may be appropriate for newborn screening.
- Develop and improve screening and diagnostic tests.
- Develop treatment and management strategies, including identifying innovative therapies for conditions that could be detected by newborn screening.

