



NEWBORN SCREENING



Did You KNOW?

Newborn Screening is one of the most successful public health programs in the United States

History of Newborn Screening

Newborn screening (NBS) began in the 1960's with testing for a single condition, phenylketonuria (PKU). Since then, advances in technology have allowed states to screen for dozens of serious conditions that are not apparent at birth but require early detection for effective treatment and management. Today, nearly all of the 3.6 million babies born each year in the U.S. are screened, saving or improving thousands of lives annually. NBS is widely recognized as one of the most successful public health initiatives of the past 50 years.

What NBS Includes

Type of Exam	Purpose
Hearing Test	Identifies congenital hearing loss
Pulse Oximetry	Detects critical congenital heart disease
Blood Test (heel prick)	Screens for a variety of conditions, majority of which are genetic

Timeline of NBS Policy Development

NBS has steadily evolved over the past two decades, guided by federal support and recommendations. The Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), together with ACMG and other partners, played a crucial role in identifying conditions appropriate for the Recommended Uniform Screening Panel (RUSP). [The timeline below highlights key milestones in this progress and recent policy changes.](#)

How NBS Programs Work

Each state and territory operate their own NBS programs, but key federal partners play a role in advancing and supporting the system, such as:

- Health Resources and Services Administration (HRSA)
- National Institutes of Health (NIH)
- Centers for Disease Control and Prevention (CDC)
- Agency for Healthcare Research and Quality (AHRQ)
- Food and Drug Administration (FDA)

- **2003** – ACHDNC formed to advise HHS on newborn screening policies.
- **2005** – ACMG recommends a uniform panel of 29 conditions; ACHDNC endorses it.
- **2008** – NBSSLA signed into law; Secretary of HHS adopts ACMG list.
- **2010** – Secretary of HHS establishes the Recommended Uniform Screening Panel (RUSP) using ACMG list.
- **2024** – By 2024, RUSP had expanded to 38 core conditions and 26 secondary conditions.
- **2025** – ACHDNC terminated. Two conditions, metachromatic leukodystrophy (MLD) and Duchenne muscular dystrophy (DMD) were under review for addition to the RUSP.

The Newborn Screening Saves Lives Act

The Newborn Screening Saves Lives Act (NBSSLA), signed into law in 2008 and reauthorized in 2014, established federal support for state newborn screening programs and continued the ACHDNC. Before its passage, only 10 states and DC screened for all 29 ACMG-recommended conditions. Today, all states screen for at least 32 of 38 conditions. The law expired in 2019. Although Congress has not been able to pass reauthorizing legislation, federal agencies have continued their NBS programs.

