Newborn Screening Can Help
Ensure Every American Baby Has the
Best Chance for a Healthy Life

Newborn Screening (NBS) programs are state-run public health programs with limited federal collaboration or guidance that identify newborns with certain genetic, metabolic, hormonal or functional disorders. With early detection, affected infants can receive prompt treatment that can prevent permanent disability, developmental delay, and death.

~4 million babies screened per year¹
~12,500 babies (or 1 in 300) born each year have a condition detected through NBS²

Types of NBS
- Heel stick to collect small blood sample
- Pulse oximetry
- Hearing screen

The Federal Government’s Role
The Federal Government makes recommendations through the Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children (ACHDNC) regarding which conditions should be included on state testing panels. The list of recommended conditions is known as the Recommended Uniform Screening Panel (RUSP). Currently, there are 35 core conditions and 26 secondary conditions on the RUSP.

To be added to the RUSP, a condition must be
1. identifiable within 1-2 days after birth,
2. have a screening test available,
3. benefit from early detection and intervention and
4. have an effective treatment.

What You Can Do to Help
We urge you to support the passage of the Newborn Screening Saves Lives Reauthorization Act (H.R. 482 / S. 350) to reauthorize existing federal programs that assist states in improving and expanding their NBS programs, support parent and healthcare provider education, ensure laboratory quality and facilitate adding conditions to the RUSP.

Piper’s Story
Piper was born in Wisconsin in November 2019 and NBS led to a diagnosis of spinal muscular atrophy (SMA), a rare muscle-wasting disease. The most severe form of SMA takes away a person’s ability to walk, talk, swallow and breathe, often becoming fatal by age 2. Wisconsin started testing for SMA via NBS the month before Piper was born. Piper was the first newborn in Wisconsin to test positive for SMA and Piper was also the first child identified through NBS to receive a new gene therapy treatment for SMA in December 2019. She received this therapy before developing any signs of weakness due to the disease. According to Piper’s mom, “the fact that we were able to catch it before there’s any loss of function is just amazing.” Indeed. Had Piper been born six weeks earlier, or in a state that does not screen for SMA, she may not have even received a diagnosis yet, let alone a treatment.

¹ www.nichd.nih.gov/health
² www.nichd.nih.gov/health
NBS Operates Unevenly, as Each State Has its Own Program

Each state's health department implements its own NBS program, and each state funds its NBS program differently. In some states, departments of health determine when to add NBS tests for newly added conditions via regulatory decision-making while other states require legislative action to expand NBS. Ultimately, it is the departments of public health that create and implement processes for collection of specimens, performing tests and developing follow-up procedures once test results are received. This map highlights the state-by-state approach to NBS. The number of total conditions screened for ranges from 31 to 68, but not one of the 50 states or 4 territories screens for all 35 RUSP core conditions and all 26 RUSP secondary conditions.

This uneven operation by the various U.S. states and territories has real-world consequences. As one example, California is a leader in NBS by screening for a total of 64 conditions, including all 35 core conditions, 22 of the secondary conditions, and an additional 7 conditions not on the RUSP.

Notwithstanding California’s leadership in NBS, other states screen for conditions that California does not. Utah, for example, screens for a disease called guanidinoacetate methyltransferase (GAMT) while California doesn’t. During the COVID lockdown in April 2020, Stewart and Becky Tribe decided to move from California to Utah. When the Tribe’s son was born in late 2020 in Utah, he was screened for GAMT and diagnosed with the disease. According to Mr. Tribe, the move was “an impulsive decision at the time that we now recognize as nothing short of an alignment of stars for our family and newborn son. Had we not moved and delivered [our son] in a hospital in Utah, he never would have been screened for GAMT. Without Utah’s newborn screening we’d likely spend years frantically searching for a cause to [our son’s] developmental delays... We’re stunned by the serendipity of it all....” Serendipity should not determine the health and development of America’s newborns.

Current Status of NBS on the Federal Level

The Newborn Screening Saves Lives Act (the Act) was passed in 2008, which established the ACHDNC as well as national NBS guidelines and funding to help facilitate comprehensive NBS in all 50 states as well as DC, Guam, Puerto Rico and the Virgin Islands. Before passage of the Act, the number and quality of NBS tests varied greatly from state to state.

In 2007, only 10 states and DC required infants to be screened for all core conditions on the RUSP. Today, all 50 states, DC and Puerto Rico screen for at least 30 of the 35 core conditions on the RUSP; the Virgin Islands and Guam screen for 24 and 28 core conditions, respectively.

The Act was reauthorized in 2014 but expired on September 30, 2019.

What You Can Do to Help

The Act has been a tremendous success in facilitating comprehensive NBS in all 50 states as well as DC, Guam, Puerto Rico and the Virgin Islands. We urge you to support the passage of the Newborn Screening Saves Lives Reauthorization Act (H.R. 482 / S. 350) to reauthorize existing federal programs that assist states in improving and expanding their NBS programs, support parent and healthcare provider education, ensure laboratory quality and facilitate adding conditions to the RUSP.