



Did You Know?

- The national [Recommended Uniform Screening Panel](#) includes 35 core conditions and 26 secondary conditions recommended for newborn screening programs.
- State newborn screening programs reach about [4 million babies](#) and identify about [12,900 babies](#) with a newborn screening disorder each year.
- Most states charge a fee [between \\$30 and \\$203](#) for newborn screenings, which are generally covered by private health insurance, Medicaid or the Children's Health Insurance Program.

Early Detection, Diagnosis and Treatment Through Newborn Screening

BY KELSIE GEORGE

Early detection of certain conditions through [newborn screening](#) can prevent severe cognitive and physical disabilities, and even death. Each year, about [4 million U.S. babies](#) are screened for congenital conditions using a heel stick to collect a blood sample, pulse oximetry to test blood oxygen levels and hearing screening. These tests identify an estimated [12,900 infants](#) with rare conditions such as cystic fibrosis, sickle cell disease, congenital hypothyroidism and hearing loss. The screening process helps health professionals identify and treat conditions before symptoms occur.

Each state has its own newborn screening program and decides which conditions to include within screening panels. To determine which conditions to include, [federal and state advisory committees](#) examine if:

- Screening is necessary.
- There is a significant risk of disability or death without prompt treatment.
- Effective treatment is possible.
- Treatment is more beneficial in the newborn period than later in life.
- Treatment and counseling are widely available.
- The benefits to society outweigh the costs of screening.

Many newborn screening panels include [rare diseases](#) and conditions, allowing for infants and their families to secure potentially life-saving treatments. Diagnosis and treatment for these conditions is limited and expensive, costing up to [hundreds of thousands of dollars each year](#).

When deciding which conditions to include, states balance the costs of newborn screening and rare disease treatments to state Medicaid programs and families with the costs of undiagnosed and untreated rare diseases that can lead to long-term disabilities or death. For example, [Washington](#) found screening for severe combined immunodeficiency significantly reduced both mortality and medical costs, deeming it cost effective to include in the state's newborn screening program.

Federal Action

The secretary of the U.S. Department of Health and Human Services makes evidence-based recommendations through the [Recommended Uniform Screening Panel \(RUSP\)](#), a list of 35 core conditions every state is encouraged to include in their newborn screening program and 26 secondary conditions that can be detected by screening for core conditions. The [Advisory Committee on Heritable Disorders in Newborns and Children \(ACHDNC\)](#), established under the [Public Health Service Act](#), advises the secretary on disorders to include on the RUSP. The committee's [decision matrix](#) for newborn screening expansion includes assessing the benefits of screening and the feasibility of implementing screening at the state level. The most recent disorder added to the RUSP was spinal muscular atrophy (SMA) in 2018.

State Action

Guided by federal recommendations, states determine the disorders in their newborn screening programs and the financing of laboratory, follow-up and program management costs. [All states](#) require newborn screening and include the majority of conditions recommended in the RUSP, but it may take states several years to fully implement new recommendations. States sometimes add a disorder to the panel that is not recommended by the RUSP. [New York](#) became the first state to screen for Krabbe disease in 2006, but the [ACHDNC](#) voted in 2009 not to add it to the RUSP without further information on disease types, screening methods and treatment effectiveness.

The process to add new disorders to the newborn screening panel varies by state. Some states set conditions through statute, while others require approval by the state department of health or an advisory board. [Nebraska](#) added SMA and [South Carolina](#) added Krabbe disease to their newborn screening panels through legislation in 2019 and 2020, respectively. [Louisiana](#), through a resolution, urged its department of health to study the costs and benefits of adding mucopolysaccharidosis type I and Pompe disease to its screening panel. [Oregon](#)

established the Newborn Bloodspot Screening Advisory Board through legislation in 2019, which [considered adding SMA](#) to the state's newborn screening panel in 2020 but did not reach the consensus necessary to approve the addition. [Virginia](#) requires the department of health to review national recommendations biennially and to consult with the Virginia Genetics Advisory Committee on changes to its core panel of heritable disorders and genetic diseases for newborn screening.

Financing and payment for newborn screening programs also vary. Most states use a [fee-based approach](#) to fund newborn screening programs to ensure consistent revenue streams and to cover laboratory expenses, follow-up services and program management. [Birthing centers and hospitals](#) either bill directly or include a fee for newborn screening in maternity charges, which are typically covered by private health insurance, Medicaid or the Children's Health Insurance Program. The ACA [requires health plans to cover screenings](#) included on the RUSP, but some states establish their own requirements for coverage. The [District of Columbia](#) requires individual and group health plans to cover the cost of newborn screenings.

[North Carolina](#) charges newborn screening fees to hospitals to cover the cost of laboratory services to process results. [Utah](#) also charges fees to hospitals and [added a requirement](#) that Medicaid and the state employee health plan cover genetic testing for conditions within the newborn screening program. [Colorado](#) created a newborn screening and genetic counseling fund in 2018 to cover the costs associated with newborn screening, follow-up care, genetic counseling and education programs.

[Screening tests](#) identify infants who may have a particular condition but cannot diagnose the condition. Newborns with a positive screening result are referred to specialty health care providers for diagnostic testing—to confirm or rule out the condition—and treatment if available. State public health agencies play an important role in ensuring follow-up with families, using [disease tracking systems](#) and additional support programs to ensure newborns receive the care they need. [Indiana](#) authorized the use of its immunization data registry to store and release newborn screening information maintained by the department to ease access for providers and patients. [Pennsylvania](#) established the Newborn Screening and Follow-up Program to strengthen follow-up services such as referrals, confirmatory testing, assessment and diagnosis of children with abnormal or inconclusive screening results. [Maryland](#) added support for families through counseling and education services after a newborn tests positive for sickle cell disease.

Additional Resources

- [Maternal and Child Health Database, NCSL](#)
- [Rare and Orphan Diseases, NCSL](#)
- [Conditions Screened by State, Baby's First Test](#)
- [Newborn Screening Information Center, Health Resources & Services Administration](#)
- [Recommended Uniform Screening Panel, Health Resources & Services Administration](#)
- [NewSteps: Newborn Screening Status for All Disorders by State](#)

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