Surge to Save Newborns

Accelerating Lifesaving Screening for Every Newborn

States need a surge of funding to screen every baby, in every state, for every recommended condition.

Newborn screening (NBS) saves lives, but only if we fund it.

A simple test performed on newborns identifies those at risk for serious and treatable rare health conditions. NBS detects metabolic disease, blood disorders, immune deficiencies, neuromuscular disorders and others, including conditions like critical congenital heart disease, cystic fibrosis, and spinal muscular atrophy (SMA). Early detection creates an opportunity for early treatment to prevent irreversible brain damage, lifelong disability, or even death. [1]

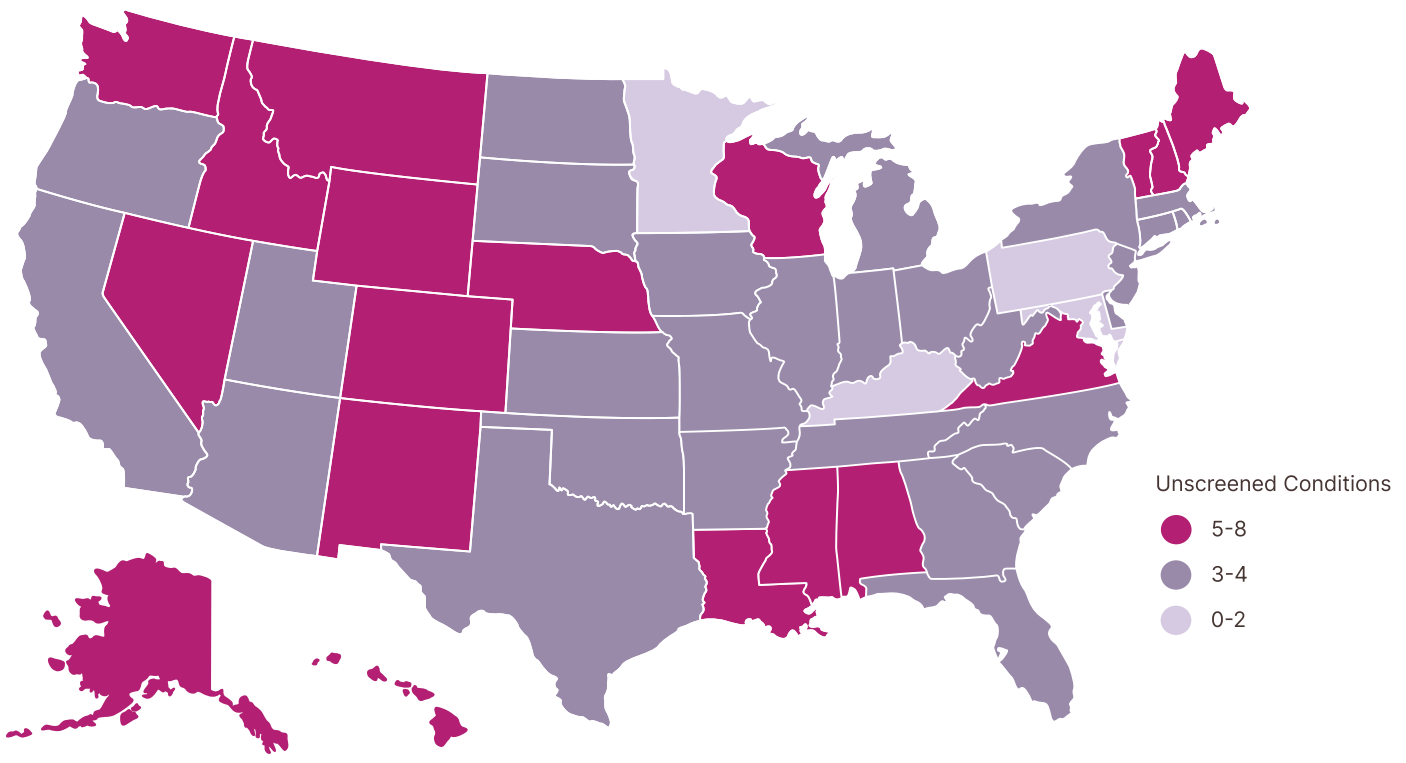
NBS is credited with identifying treatable conditions in an estimated 14,000 newborns each year and is widely considered one of the most impactful public health tools in history. [2]

The U.S. Department of Health and Human Services (HHS) Recommended Uniform Screening Panel (RUSP) is a national list of rare health conditions that experts recommend including in state-based newborn screening programs. It includes 40 core conditions with proven, effective screening and treatment options and 26 secondary conditions that may be identified through core screening or follow-up testing. Conditions are added to the RUSP upon rigorous, evidence-based evaluation and confirmation of an effective treatment option.

Time is of the essence to ensure all states screen their newborns. Too many are falling through the current system.

When experts update the RUSP, it signals to the states that a condition is recommended for screening, but many states lack the funding and infrastructure to fully implement new screenings in a timely manner. The longer it takes for states to begin screening for a new condition, the more babies are at risk of not receiving a diagnosis and treatment in the critical early window that can help them survive these often-life-threatening conditions.

Number of Expert-Recommended, yet Unscreened Conditions



5-6 years

Average time for a state to implement screening for a new RUSP-approved condition. [3]

10 years

Up to 10 years or more for all 50 states and U.S. territories to implement and begin screening for a RUSP-approved condition. [4]

One Example:

X-ALD screening is still missed for many, a decade later. RUSP-approved X-linked adrenoleukodystrophy (ALD), causes adrenal failure and rapid, irreversible brain degeneration in childhood if not identified early through NBS. Treatment can halt disease progression but only if started before symptoms appear. [5]

In 2016, X-ALD was RUSP-approved, but has been a slow addition to NBS programs.

2 states still do not screen for X-ALD a decade later, leaving babies at risk of missed screenings and the chance for early intervention.

A surge of funding could save thousands of babies.

Some states are missing the opportunities that cost-effective screening provides due to implementation delays and disjointed resources. Funding support is urgently needed to overcome and prevent screening delays.

There is existing precedent for special surge funding, creating a clear roadmap for action.

The Special Diabetes Program created in 1998 is heralded as catalyzing progress and fostering unique collaborations in diabetes research. This special statutory funding program is a model for how RUSP implementation support could be administered to state NBS programs.

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Conditions that are RUSP-approved but not yet screened for in every state, some of which were recommended over 10 years ago.

>$1m

Costs to families associated with undetected rare disease, which in many cases can be averted through NBS. [6]

$173M

One-time funding allocation over five years needed for all states to screen for all RUSP-approved conditions.

One-time funding, long-term cost-effective impact:

This small, but crucial investment could determine whether babies live or die, prevent life-long disability, and spare families and the government millions of dollars in medical costs—all for a fraction of the HHS budget.

Now is the time for Congress and the Administration to act to ensure screening for every recommended condition for every newborn, in every state.

References

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[5] Newborn screening: public health practice and policy considerations. https://pmc.ncbi.nlm.nih.gov/articles/PMC7041623/.
[6] Time to Transplant in X-linked Adrenoleukodystrophy. https://pmc.ncbi.nlm.nih.gov/articles/PMC9086106/.

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