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]

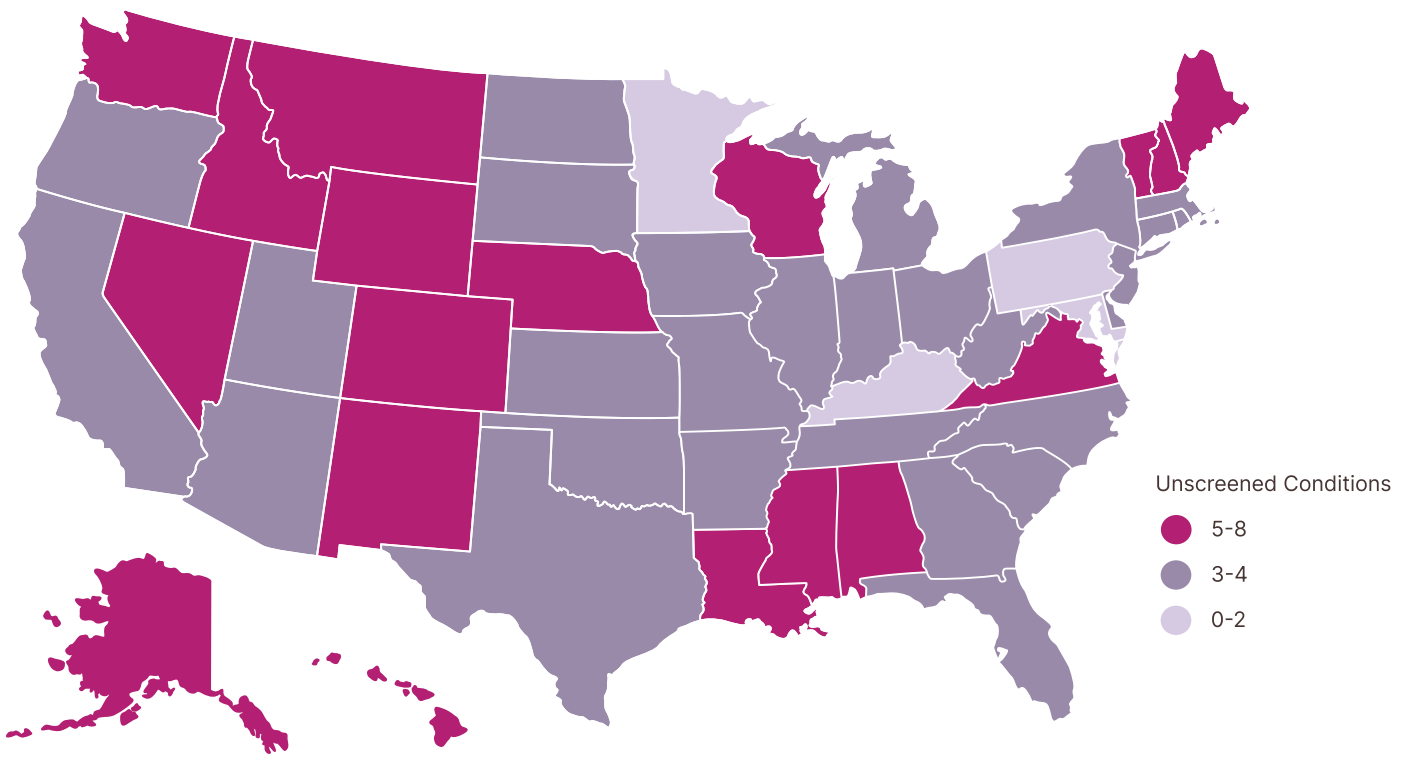
NBS is credited with identifying treatable conditions in an estimated 14,000 newborns each year and is widely considered one of the most impactful public health tools in history.[2]

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]

A surge of funding could save thousands of babies. Congress has a solution.

8 conditions

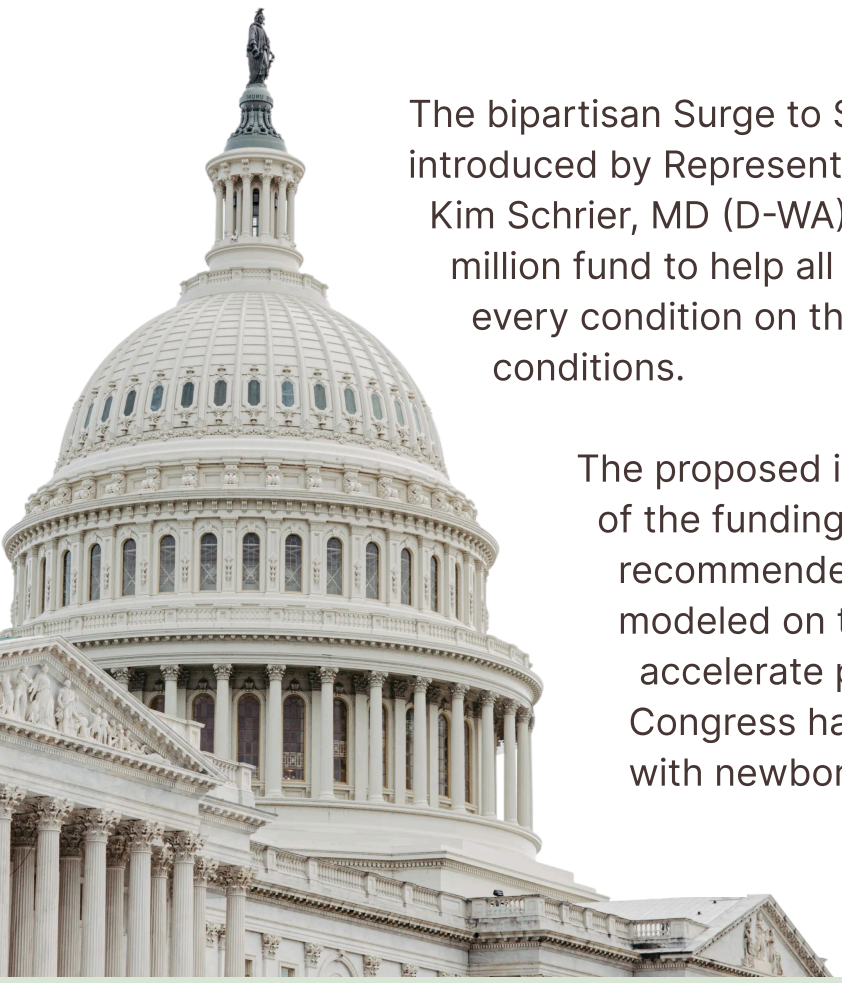
that are RUSP-approved but not screened for in every state, some of which were recommended over 10 years ago.

98% of states

are not yet screening for all 40 RUSP-approved conditions.[6]

>$1million

Costs to families associated with undetected rare disease, which in many cases can be averted through NBS.[7]



The bipartisan Surge to Save Newborns Act (H.R. 10571), introduced by Representatives Nick Langworthy (R-NY) and Kim Schrier, MD (D-WA), would provide a one-time $175 million fund to help all 50 states screen newborns for every condition on the RUSP as well as two future conditions.

The proposed investment is based on a 2026 study of the funding required to implement all RUSP-recommended conditions.[8] The legislation is modeled on the use of dedicated funding to accelerate progress in diabetes research. Congress has a unique opportunity to do so again with newborn screening.

X-ALD screening is still missed for many, a decade after it was first recommended for screening.

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.

The Surge to Save Newborns coalition is calling on lawmakers to help save as many babies as possible from preventable early death or lifelong disability by cosponsoring the Surge to Save Newborns Act.

ALD Alliance
ALD Connect
Aicardi-Goutieres Syndrome Advocacy Association
Association for Creatine Deficiencies
Believing for Bryleigh Foundation
Conner's Crusade
CTX Alliance
Cure ALD
HCU Network America
Hunter's Hope Foundation
Judson's Legacy
Katelynn's Butterfly Kisses
KrabbeConnect
Little Hercules Foundation
MLD Foundation
Parent Project Muscular Dystrophy
Project Alive
Remember The Girls
The Global Foundation for Peroxisomal Disorders
Sereno Warriors
United Leukodystrophy Foundation
United MSD Foundation

References

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[4]Genetic insights and newborn screening advances. https://www.frontiersin.org/journals/genetics/articles/10.3389/fgene.2022.867337.
[5] Newborn screening: public health practice and policy considerations. https://pmc.ncbi.nlm.nih.gov/articles/PMC7041623/.
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