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The Surge to Save Newborns Coalition Applauds Introduction of Landmark Bipartisan Legislation to Expand Lifesaving Newborn Screening Nationwide

The Surge to Save Newborns Act transforms the coalition's central goal into legislation - creating a path to implement every expert- recommended newborn screening across all 50 states.

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The Surge to Save Newborns coalition applauds the introduction of the bipartisan Surge to Save Newborns Act by Congressman Nick Langworthy (NY) and Congresswoman Kim Schrier, MD, alongside several original sponsors. The landmark legislation would establish a one-time $175 million special fund to help every state implement newborn screening for every condition recommended by the federal Recommended Uniform Screening Panel (RUSP).

The bill's introduction marks a defining milestone for the movement to save as many babies as possible from preventable early death and lifelong disability. “This is the moment our coalition’s goal advances from aspiration to action,” said Elisa Seeger, Founding Partner of the Surge to Save Newborns and Founder of the ALD Alliance. “The introduction of the Surge to Save Newborns Act brings us one crucial step closer to a country where a baby's zip code no longer determines whether a treatable condition is identified in time to save their life.”

Although the RUSP reflects expert consensus on serious, rare conditions that are treatable when detected early, it can take up to a decade or more for every state to begin screening for a recommended condition. A baby may be screened for a lifesaving condition in one state but not in another. For some newborns, that difference can mean life or death.

The Surge to Save Newborns Act offers a bold new approach to this persistent national problem–modeled on Congress’s successful use of dedicated funding to accelerate progress in diabetes research. Instead of leaving states to overcome implementation barriers in the absence of adequate resources, this one-time funding surge will help accelerate implementation nationwide. The $175 million investment is modeled on a 2026 study of the funding required to implement all RUSP-recommended conditions across all 50 states.

“Families affected by rare diseases understand firsthand just how much early diagnosis matters. Every delay means more babies may be born without access to lifesaving newborn screening,” said Anna Grantham, Founding Partner of Surge to Save Newborns and Director of Newborn Screening and the Leukodystrophy Care Network at Hunter's Hope Foundation. “We are deeply grateful to Representatives Langworthy and Schrier for their bipartisan leadership and for putting forward a proactive solution to help states overcome the barriers that have delayed newborn screening expansion for far too long.”

The coalition urges members of Congress to cosponsor and support the Surge to Save Newborns Act. The introduction during September's Newborn Screening Awareness Month underscores both the lifesaving power of early detection and the urgent need to ensure that every newborn has the same opportunity for a healthy future, regardless of where they are born.

The Surge to Save Newborns Act is endorsed by more than 20 patient advocacy organization members of the Surge to Save Newborns Coalition, including the ALD Alliance and Hunter's Hope. The Children's Hospital Association, Global Genes, the National Organization for Rare Disorders (NORD), and the RARE Foundation have also endorsed the bill.

Visit our Act Now page to send a letter to your Member of Congress urging cosponsorship or support for the Surge to Save Newborns Act.

Visit Congress.gov to track the bill's status including the latest cosponsorships.

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