NEWBORN SCREENING

2021

ENSURING THE US REMAINS THE WORLD LEADER IN NEWBORN SCREENING

NEWBORN SCREENING OVERVIEW

Newborn screening (NBS) is a lifesaving state public health program that identifies time-sensitive heritable conditions that are treatable when detected early. The roughly four million babies born in the US each year receive NBS, and all screening is performed in a state public health laboratory or a laboratory under state public health laboratory oversight. The process includes:

SAMPLE COLLECTION → INITIAL SCREENING → REPORT RESULTS → CONFIRMATORY TESTING → MEDICAL INTERVENTION

NEWBORN SCREENING SAVES LIVES REAUTHORIZATION ACT (HR 482 & S 350)

Enactment of the Newborn Screening Saves Lives Act in 2008 allowed great strides to be made in harmonizing and standardizing NBS programs across the nation. Reauthorization will further the lifesaving work of newborn screening programs and the federal agencies that serve newborns and their families.

	CURRENTLY FUNDED ACTIVITIES	FY22 FUNDING REQUESTS	INCREASED FUNDING WILL SAVE MORE LIVES BY:
CDC NBS QUALITY ASSURANCE PROGRAM	• **Education:** Provides technical assistance on new technologies, methodologies and disorders to state programs and healthcare professionals. • **Emergency Preparedness:** Ensures all babies are tested despite emergencies or disasters through development of a model national emergency contingency plan. • **Quality Assurance:** Provides proficiency testing and quality control for NBS laboratories. • **Test Development**: Develops tests that can screen for multiple disorders, expanding laboratory testing capabilities.	FY 2021 **$18 MILLION** FY 2022 **$30 MILLION** (necessary)	• **Accelerating Test Development and Expand Screening Panels:** Increasing the number of new disorders screened would allow more babies to be screened for more disorders faster. • **Replacing Antiquated Data Platforms:** Developing and adapting innovative data collection and bioinformatics applications will help laboratories conduct more effective data analysis and disease detection.
HRSA HERITABLE DISORDERS	• **Screening Expansion:** Provides funding for 30% of states to start testing for new disorders. • **Turn-around Time Reduction:** Decreases turn-around time for results by creating a framework and assessment tool that states can utilize to meet federal timeliness goals. • **Information Sharing:** Supports the Newborn Screening Technical assistance and Evaluation Program (NewSTEPs), an information repository hub that NBS programs nationwide use to improve their own systems. • **Quality Improvement:** Increases efficiency across the NBS system via continuous quality improvement training and resource sharing	FY 2021 **$18.9 MILLION** FY 2022 **$32 MILLION** (necessary)	• **Enhancing Screening for New Disorders:** Funding the remaining 70% of states to scale up their infrastructure (instrumentation, workforce, supplies, big data) and interoperability, and coordinating their efforts will allow new conditions to be more rapidly implemented across the US. • **Providing Robust, Integrated Follow Up Programs:** Ensuring an equitable, integrated system for follow up will support families and children beyond screening.

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