

Congress of the United States

Washington, DC 20510

May 23, 2025

The Honorable Robert Aderholt
Chair
House Appropriations Subcommittee on
Labor, Health, Human Services, and Education
United States House of Representatives
2358-B Rayburn House Office Building
Washington, D.C. 20515

The Honorable Rosa L. DeLauro
Ranking Member
House Appropriations Subcommittee on
Labor, Health, Human Services and Education
United States House of Representatives
2358-B Rayburn House Office Building
Washington, D.C. 20515

Dear Chairman Aderholt and Ranking Member DeLauro:

As you begin work on this year's budget process, we ask for continued strong support for the Centers for Disease Control and Prevention's (CDC) Newborn Screening Quality Assurance Program (NSQAP), the Health Resources and Service Administration's (HRSA) Heritable Disorders Program, and the National Institutes of Health (NIH) Hunter Kelly Newborn Screening Research Program in the FY 2026 Labor, Health and Human Services, and Education Appropriations Bill.

Additionally, we ask that you please include committee report language directing HRSA and CDC to continue prioritizing the timely implementation of newborn screening conditions with a goal of complete Recommended Uniform Screening Panel (RUSP) implementation as soon as possible.

Newborn screening is one of our nation's most successful public health programs, serving almost four million infants each year and saving countless lives through the early detection of congenital and inherited disorders that may not present clinical symptoms at birth, but can cause permanent disability or death if not detected or treated within the first few days of life.

Federal support and funding are essential to the success of our nation's newborn screening programs. State programs report a 99.9% or higher participation rate in newborn screening, which routinely includes a blood, pulse oximetry, and hearing test for the infant and leads to the early detection of diseases for more than 12,000 infants. This early detection is crucial for improving the likelihood of effective treatment and long-term healthy development for the child.

We appreciate the sustained investments made over the last few years, and we respectfully ask that you build on that strong support in FY 2026 by continuing to invest in newborn screening programs at the CDC and HRSA, including efforts to implement the Recommended Uniform Screening Panel (RUSP).

First, programs at CDC and HRSA have a significant impact on, and make critical contributions to, state newborn screening programs. The CDC's NSQAP performs quality testing for more than 500 laboratories to ensure the accuracy of newborn screening tests in the United States and

around the world. Further, the CDC helps states implement newborn screening and works with partners to develop new screening tests for specific disorders. These efforts are incredibly resource intensive, particularly due to strained public health budgets many states are facing.

Similarly, HRSA's Heritable Disorders Program provides assistance to states to improve and expand their newborn screening programs and promote parent and provider education. HRSA also supports the work of the Advisory Committee on Heritable Disorders in Newborns and Children, the HHS Secretary's advisory committee that recommends which disorders should be included on the RUSP. HRSA also provides states with assistance, and funds the National Technical Assistance Center, to help ensure every infant in every state is screened for conditions on the RUSP. With the growing number of conditions detectable at birth with an effective treatment available, additional funding for HRSA's efforts to review and recommend new screens for states is more salient than ever.

Today, only Pennsylvania and Kentucky are conducting newborn screening for all 38 RUSP-approved core conditions, 10 states screen 37, 10 states screen 36, and 28 states screen 35 or less. As this example shows, it can take states more than a decade to implement newborn screening for all RUSP approved diseases for which treatment options are available to families. These delays in adding new screens to state panels result in preventable deaths and disability. New resources will support both staffing and equipment needs in every state to include all RUSP conditions, thus avoiding these preventable deaths and disability.

NIH's Hunter Kelly Newborn Screening Research Program contributes to advancing newborn screening in several key areas including identifying, developing, and testing promising new screening technologies; increasing the specificity of newborn screening; expanding the number of conditions for which testing is available; and developing experimental treatments and disease management techniques. As such, we ask that you continue to provide robust and predictable increases for the Hunter Kelly Program.

Thank you for your continued support of the newborn screening programs that are advancing the nation's newborn screening system and saving lives.

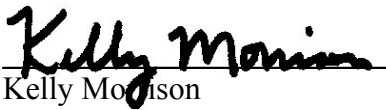
Sincerely,



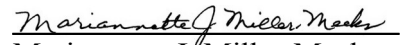
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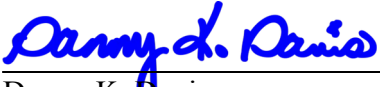


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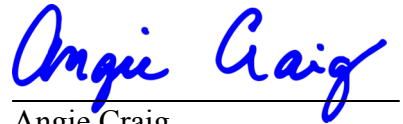


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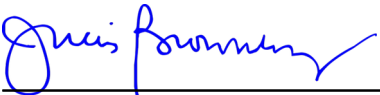
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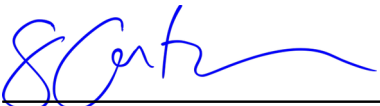
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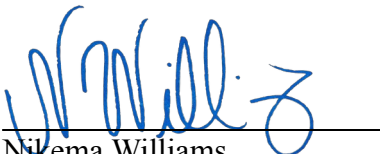
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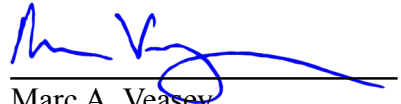
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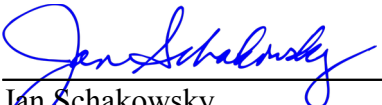
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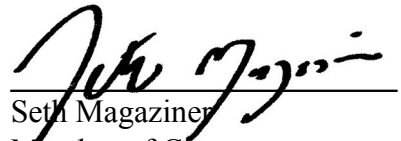
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