United States Senate

WASHINGTON, DC 20510

April 21, 2026

The Honorable Shelly Moore Capito
Chairwoman
Senate Committee on Appropriations on
Labor, Health and Human Services,
Education, and Related Agencies
United States Senate
Washington, D.C. 20510

The Honorable Tammy Baldwin
Ranking Member
Senate Committee on Appropriations on
Labor, Health and Human Services,
Education, and Related Agencies
United States Senate
Washington, D.C. 20510

Dear Chairwoman Capito and Ranking Member Baldwin:

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 Hunter Kelly Newborn Screening Research Program at the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) in the FY 2027 Labor, Health and Human Services, and Education Appropriations Bill.

Additionally, we ask that you please include committee report language directing the Department of Health and Human Services to ensure the critical work of the Advisory Committee on Heritable Disorders in Newborns and Children continues particularly the addition of new conditions to the Recommended Uniform Screening Panel (RUSP).

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 2027 by continuing to invest in newborn screening programs at the CDC and HRSA, including efforts to implement the Recommended Uniform Screening Panel (RUSP).

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. Increasing appropriations for CDC's newborn screening programs would facilitate an expansion of their training programs and quality assurance assistance to states.

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 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. While most states apply for HRSA's Propel and Co-Propel grant programs, not all states receive assistance purely due to limited funding available. 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 disorders for states to screen is more salient than ever.

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 National Institutes of Health (NIH) and its centers.

In conclusion, prolonged delays in adding new screens to state panels result in preventable deaths and disability. Increased resources will support staffing, equipment, quality testing, and technical assistance to states as they work to include all RUSP conditions on their panels, thus avoiding these preventable deaths and disability. Thank you for your continued support of the newborn screening programs that are advancing the nation's newborn screening system and savings lives.

Sincerely,

Kirsten Gillibrand
United States Senator

James Lankford
United States Senator

Peter Welch
United States Senator

Andy Kim
United States Senator

Roger Marshall, M.D.
United States Senator

Lisa Blunt Rochester
United States Senator

Jon Ossoff
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