

United States Senate

WASHINGTON, DC 20510

July 8, 2021

The Honorable Patty Murray
Chair
Subcommittee on Labor, Health and
Human Services, and Education
Senate Committee on Appropriations
Washington, DC 20510

The Honorable Roy Blunt
Ranking Member
Subcommittee on Labor, Health and
Human Services, and Education
Senate Committee on Appropriations
Washington, DC 20510

Dear Chair Murray and Ranking Member Blunt,

Newborn screening is one of our nation's most successful public health programs, serving almost 4 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. These successes have been made possible by your Subcommittee's investment in 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).

We appreciate the new investments made in these programs in fiscal year FY 2021, and as you develop the appropriations legislation for Fiscal Year 2022, we respectfully ask that you to prioritize the highest possible funding level for both newborn screening programs at CDC and HRSA in the Labor, Health and Human Services, and Education Appropriations bill. Further, we ask that you continue to provide robust and predictable increases for the National Institutes of Health (NIH) and its centers.

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.

HRSA's Heritable Disorders Program provides assistance to states to improve and expand their newborn screening programs and to promote parent and provider education. HRSA also supports the work of the Advisory Committee on Heritable Disorders in Newborns and Children, which provides states with a Recommended Uniform Screening Panel (RUSP) to help ensure every infant in every state is screened for conditions that have a recognized treatment.

The 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. This work promotes the continued improvement of the newborn

screening process, increasing the resources available to doctors for treating diseases that, when left undiagnosed, may cause irreversible neurological, intellectual, and physical damage.

Thank you for your past support of the newborn screening programs that are advancing the nation's newborn screening system and saving lives. We urge you to continue this support by providing sustained funding for both CDC and HRSA programs, as well as for biomedical research at NIH in FY 2022. Thank you for your consideration of this request.

Sincerely,



Kirsten Gillibrand
United States Senator



James Lankford
United States Senator



Debbie Stabenow
United States Senator



Roger Marshall
United States Senator