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Reps. Roybal-Allard, Simpson, Clark, Herrera Beutler Celebrate House Passage of Newborn Screening Saves Lives Reauthorization Act

Washington, DC – Tonight, **Congresswoman Lucille Roybal-Allard (CA-40)**, **Congressman Mike Simpson (ID-02)**, **House Democratic Caucus Vice Chair Katherine Clark (MA-05)**, and **Congresswoman Jaime Herrera Beutler (WA-03)** celebrated the House’s passage of the Newborn Screening Saves Lives Reauthorization Act (H.R. 2507), a bill to eliminate preventable newborn deaths and severe disabilities through the increased use of comprehensive and standardized newborn screening tests. This bipartisan legislation reauthorizes critical federal activities that help states improve and expand their newborn screening programs, support newborn screening education for parents and providers, and ensure laboratory quality and surveillance. The bill renews funding for the programs of the Newborn Screening Saves Lives Act, which was originally introduced in the House by Reps. Roybal-Allard and Simpson, and was passed and signed into law in 2008. The Newborn Screening Saves Lives Act was last reauthorized in 2014. A Senate companion bill, S. 2158, was introduced by Senators Maggie Hassan (D-NH) and Cory Gardner (R-CO).

“I am thrilled that the House has passed my lifesaving bill to help ensure all babies receive the comprehensive and consistent testing they need to live healthy and productive lives,” said Rep. Roybal-Allard. **“I’m grateful to my colleagues Mike Simpson, Katherine Clark, and Jaime Herrera Beutler for their partnership as we worked to pass this bill through the House. Newborn screening is an amazing public health success story – a demonstration of the amazing things that can happen when private organizations, public institutions, industry, advocates, scientists, providers, and parents all work together toward the common goal of a healthier future for our children.”**

“I applaud the House of Representatives for the overwhelming bipartisan support for the Newborn Screening Saves Lives Reauthorization Act,” said Rep. Simpson. **“Early detection and preventative medicine are some of the best ways to save lives and reduce the cost of care. There is perhaps no greater example of this than newborn screening and this bill delivers the tools that allow nearly 12,000 babies each year to identify conditions that are rare but treatable. I thank my friend and colleague Congresswoman Roybal-Allard for her work to get this bill through the House. It is important that the Senate act before the authorization expires at the end of September.”**

“I’m incredibly grateful for the support of my House colleagues in passing the Newborn Screening Saves Lives Reauthorization Act,” said Vice Chair Clark. **“This bill will fund essential programs and research to ensure that infants can receive effective, comprehensive screenings for treatable conditions. I am proud to co-lead this bipartisan bill that will help our youngest Americans have happy, healthy lives.”**

“Early identification of health conditions in newborns can save their lives,” said Rep. Herrera Beutler. **“As a mom with a new baby, and on behalf of all the other moms and moms-to-be in Southwest Washington, I’m so pleased we advanced this bipartisan solution today to allow babies to receive life-saving screenings.”**

In America, newborn screening is a state-run public health system in which all newborn infants receive a simple blood test that identifies specific genetic, metabolic or functional disorders that may not be apparent at birth. If left untreated, these conditions can cause serious illness, lifetime disabilities, and even death. Before the development of newborn screening tests more than fifty years ago, these illnesses would have gone undetected until symptoms appeared. Newborn screening gives these children have the chance to live relatively normal lives.

Before the original Newborn Screening Saves Lives Act was enacted in 2008, only ten states and the District of Columbia required infants to be screened for a complete panel of recommended disorders, and there was no federal repository of information on the diseases. Today, 49 states and the District of Columbia screen for at least 31 of the 35 currently recommended core conditions, and parents and professionals have access to a central database of newborn screening information when a baby is diagnosed with one of these disorders.

Over the past decade, newborn screenings and follow-up systems have improved dramatically, and several new screenings have been added. Passing H.R. 2507 will maintain this progress, and ensure that the advisory committee created under the original Newborn Screening bill continues its critical work of recommending new screenings to state programs. H.R. 2507 will also address newborn screening gaps and challenges that still remain, including discrepancies in the number of screening tests given from state to state – discrepancies which result in approximately 1,000 infants each year who face death or permanent disability because they do not receive core newborn screening tests to identify treatable disorders. The Newborn Screening Saves Lives Reauthorization Act will help to avoid these preventable tragedies by providing states with the resources they need to improve their newborn screening programs and to uniformly test for all recommended disorders. It will also provide states with assistance in developing follow-up and tracking programs. These provisions will help our financially burdened health care system by saving billions of dollars throughout the lives of these children.

In addition, the bill renews the Secretary’s Advisory Committee for Heritable Disorders, and requires the Centers for Disease Control and Prevention (CDC) to ensure the quality of laboratories involved in newborn screening. The bill also continues the Hunter Kelly Newborn Screening Program, which helps researchers at the National Institutes of Health to develop better detection, prevention, and treatment strategies. This reauthorization bill also commissions a National Academy of Medicine (NAM) report to make consensus recommendations to shift to a 21st century newborn screening system.

Organizations endorsing the Newborn Screening Saves Lives Reauthorization Act include the American Academy of Pediatrics; American Association for Clinical Chemistry; American College of Medical Genetics and Genomics; Association of Maternal & Child Health Programs; Association of Public Health Laboratories; Cystic Fibrosis Foundation; Cure SMA; EveryLife Foundation for Rare Diseases; Expecting Health at Genetic Alliance; Hunter's Hope Foundation; Immune Deficiency Foundation; March of Dimes; Muscular Dystrophy Association; National Organization for Rare Disorders (NORD); and Parent Project Muscular Dystrophy (PPMD).

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