



Make today a breakthrough.

February 10, 2021

The Honorable Lucille Roybal-Allard
United States House of Representatives
Washington DC 20515

The Honorable Michael K. Simpson
United States House of Representatives
Washington DC 20515

The Honorable Katherine M. Clark
United States House of Representatives
Washington DC 20515

The Honorable Jaime Herrera Beutler
United States House of Representatives
Washington DC 20515

Dear Representatives Roybal-Allard, Simpson, Clark, and Herrera Beutler,

Cure SMA is pleased to support the reintroduction of the Newborn Screening Saves Lives Reauthorization Act (H.R. 482). Your bipartisan legislation would extend and strengthen federal newborn screening activities that help states improve their newborn screening programs, ensure the accuracy and quality of newborn screening tests, and promote the health and well-being of children across the country.

Cure SMA is the leading national organization that represents individuals with spinal muscular atrophy (SMA) and their families. SMA is a genetic neuromuscular disease that robs individuals of physical strength, taking away their ability to walk, eat, and breathe. SMA impacts 1 in 11,000 births in the United States and approximately 1 in 50 people is a genetic carrier of SMA. If both parents are SMA carriers, every child they have together has a 25% chance of being diagnosed with SMA, regardless of race, ethnicity, and gender.

Past federal newborn screening activities and investments have saved and improved lives in the SMA community. In 2018, the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) recommended that states screen for SMA, the leading genetic cause of infant death. Since SMA was added to the Recommended Uniform Screening Panel (RUSP), 33 states, including California, Massachusetts, and Washington, have started screening for SMA, covering nearly 70% of all babies born in the United States. Newborn screening shortens the time it takes to receive a diagnosis, which allows parents of babies born with SMA to make timely decisions about treatment and care. The SMA community now has three effective U.S. Food and Drug Administration-approved treatments that make it possible, if given early, for individuals with SMA to achieve unprecedented milestones and stop or slow the degenerative course of the disease. In its recent two-year follow-up SMA report, ACHDNC found that newborn screening of SMA likely resulted in *“reduced deaths and cases of ventilator-dependence by 1 year of life.”*

Your legislation (H.R. 482) would extend ACHDNC and ensure that states receive critical resources and support from the Centers for Disease Control and Prevention



and the Health Resources and Services Administration to help them implement and improve their screening programs for SMA and other conditions. Your legislation would also require the National Academy of Medicine to develop recommendations to modernize the nation's newborn screening system.

Cure SMA and our network of families and individuals with SMA strongly support the Newborn Screening Saves Lives Reauthorization Act (H.R. 482). We look forward to working with you and your staffs to help ensure this important bipartisan legislation is approved by the 117th Congress. For more information, your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004.

Sincerely,

A handwritten signature in black ink that reads "K. A. Hobby".

Kenneth Hobby
President
Cure SMA

A handwritten signature in black ink that reads "Maynard Friesz".

Maynard Friesz
Vice President of Policy & Advocacy
Cure SMA