



Make today a breakthrough.

June 28, 2021

Re: Please Support Newborn Screening Legislation and Funding

Dear Senator,

As the leading national organization that represents individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), **Cure SMA respectfully asks that you invest in newborn screening activities at the U.S. Department of Health and Human Services (HHS) and reauthorize the Newborn Screening Saves Lives Reauthorization Act (S. 350).**

In July 2018, the federal government [recommended](#) that states begin to screen newborns for SMA, an inherited neurodegenerative disease that robs individuals of physical strength, taking away their ability to walk, eat, and breathe. Less than 3 years after the federal recommendation, [three-quarters](#) of all states screen for SMA covering more than 8 in every 10 babies born in this country. An additional 4 to 5 states could begin SMA screening before the end of this year, with the remaining states scheduled for 2022 and 2023. Newborn screening is the most effective and efficient way for babies with SMA to access timely treatments and available supports.

Past congressional investments and federal policy helped lead to this significant achievement. The Newborn Screening Saves Lives Reauthorization Act (NBSSLRA) authorizes the [Advisory Committee on Heritable Disorders in Newborns and Children](#) that made the original SMA recommendation in 2018. The HHS newborn screening activities, which are authorized through NBSSLRA and funded through the Labor-HHS-Education Appropriations bill, assist states in screening for SMA and other newly recommended conditions, ensuring the quality of existing tests, and educating parents about newborn screening and possible treatments. These federal programs, along with leadership at the state level, have helped to make SMA one of the fastest implemented newborn screening disorders.

As an influential U.S. Senator, you can help ensure that all babies born in this country are screened for SMA and other recommended disorders by:

- **Sponsoring and supporting the Newborn Screening Saves Lives Reauthorization Act (S. 350).** Last week, the U.S. House of Representatives [approved](#) its version (H.R. 482) of the legislation.
- **Funding federal newborn screening activities in the FY 2022 Labor-HHS-Education Appropriations bill**, including:

- \$28.8 million for the Health Resources and Services Administration's Heritable Disorders Programs; and
- \$28 million for the Centers for Disease Control and Prevention's Newborn Screening Quality Assurance Program.

To learn more about the newborn screening progress made since SMA was added to the RUSP, visit the Cure SMA [July 2021 SMA Newborn Screening Report Card](#). Thank you for considering our views.

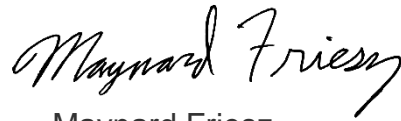
Sincerely,



Kenneth Hobby
President



Mary Schroth, M.D.
Chief Medical Officer



Maynard Friesz
Vice President of Policy