



July 2, 2020

Make today a breakthrough.

The Honorable Kay Ivey
Governor
State of Alabama
State Capitol, 600 Dexter Avenue
Montgomery, AL 36130-2751

Dear Governor Ivey,

This month marks the two-year anniversary since the U.S. Department of Health and Human Services Secretary recommended that spinal muscular atrophy (SMA) be added to state newborn screening panels. Cure SMA is pleased to provide a **progress update on screening of SMA across the country** and to outline the **remaining states and catch-up actions needed** to reach all newborns, including those born in Alabama.

SMA is a progressive neurodegenerative disease that robs an individual of their ability to walk, swallow, and—in the most severe cases—even breathe. SMA, which impacts approximately 1 in every 11,000 births in the U.S., is one of the leading genetic causes of death for infants. In Alabama, more than 97,000 residents are SMA carriers. If both parents are SMA carriers, every child they have together has a 25% chance that the child will have SMA, regardless of race, ethnicity, and gender. The good news is that there are multiple U.S. Food and Drug Administration approved treatments for SMA that make it possible for individuals with SMA to achieve developmental milestones and live full and productive lives.

In July 2018, SMA was added to the federal Recommended Uniform Screening Panel (RUSP), an important step that triggers state action to adopt and implement newborn screening of the condition. **Within the last 24-months, SMA screening has crossed the midway point—both in number of states and the percentage of newborns who are now screened for SMA.**

- **31 states currently screen newborns for SMA.**
 - **26 states have implemented permanent SMA newborn screening programs**, including Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kansas, Kentucky, Maryland, Michigan, Minnesota, Mississippi, Missouri, New Hampshire, New York, Pennsylvania, Rhode Island, Tennessee, Utah, Vermont, West Virginia, Wisconsin, and Wyoming.
 - **5 additional states are screening newborns for SMA through pilot programs**, including Iowa, Massachusetts, North Carolina, North Dakota, and Ohio.
- **Approximately 65% of babies born in the U.S. are now screened for SMA through the existing 31 permanent and pilot state SMA screening programs.**

- The percentage of newborns screened in the U.S. is expected to increase to more than 70 percent by the end of the year through the anticipated starts of new SMA newborn screening programs in Virginia, Washington, New Jersey, and other states.
- **Alabama is among the remaining 19 states and the District of Columbia that have not yet implemented SMA screening.**

Despite the progress toward newborn screening of SMA, **the United States remains well short of the 100% implementation target.** Cure SMA strongly believes that all newborns, regardless of their birth state, should be screened for SMA, especially given the availability of life-saving and life-changing treatments for SMA.

Alabama represents a priority state for Cure SMA in our nation's goal of universal SMA newborn screening. We recognize the foundational work of the Alabama Department of Public Health in the 2 years since the federal SMA recommendation. We also appreciate the commitment of State Health Officer Dr. Harris to implement SMA and other RUSP conditions not currently being screened in Alabama. As chief executive of your state, you play a key and influential role in ensuring Alabama is not one of the last states to implement newborn screening of SMA.

CURE SMA REQUEST:

On behalf of Alabama families impacted by SMA, Cure SMA respectfully asks that you:

- **Fully support the Alabama Department of Public Health in their work toward state implementation of newborn screening of SMA; and**
- **Provide a written timeline that summarizes next steps and activities that Alabama plans to take to accelerate implementation of SMA screening of Alabama newborns.**

Recognizing your focus on addressing COVID-19 in your state, Cure SMA and our Alabama supporters are available to assist your Administration and other state leaders in speeding up SMA newborn screening implementation. Your staff can forward your written update to Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004. Thank you for your consideration.

Sincerely,



Kenneth Hobby
President



Mary Schroth, M.D
Chief Medical Director



Jill Jarecki, PhD
Chief Scientific Officer