



Make today a breakthrough.

January 10, 2024

Dear Member of Congress,

On behalf of individuals and families impacted by spinal muscular atrophy (SMA), **Cure SMA is pleased to report that all 50 states are now screening for the disease.** SMA is a debilitating neuromuscular disease that robs individuals of their physical strength by impairing the muscles used for breathing, eating, crawling, and walking.

Earlier this month, the final two states, Hawaii and Nevada, began testing newborns for SMA, helping reach the 50-state newborn screening threshold faster than any other condition added to the federal recommended uniform screening panel (RUSP). **This significant public health achievement would not have happened had it not been for forward-looking policies (P.L. 110-204) and public health investments supported by Congress.**

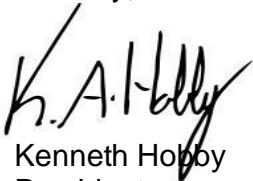
Universal newborn screening of SMA means that infants born in any of the 50 states will no longer experience the frustration of delayed diagnosis and missed opportunities for better outcomes because their families did not receive their SMA diagnosis at birth. Before newborn screening, families of children undiagnosed with SMA would spend months and sometimes years, in and out of doctors' offices, trying to figure out why their child was losing mobility or missing key developmental milestones. Newborn screening is the most effective and efficient way for babies with SMA to access timely treatments and available support.

With the successful completion of this 50-state public-private partnership, the SMA community remains focused on other SMA community priorities, which include:

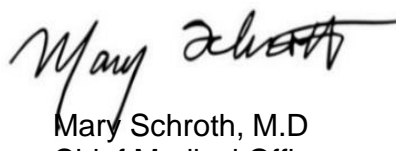
- Expanding SMA research at the National Institutes of Health into treatments that improve strength and restore function;
- Improving access to care, existing treatments, and other health services, such as in-home caregiving; and
- Addressing other barriers to independence and community living for children and adults with SMA around accessible air travel, financial security (SSI asset limit), technology, housing, and education.

Cure SMA and the SMA community look forward to working with you in 2024 on these and other important issues that impact individuals with SMA and their families. Your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at 202-871-8004 or maynard.friesz@curesma.org if they have questions or need additional information.

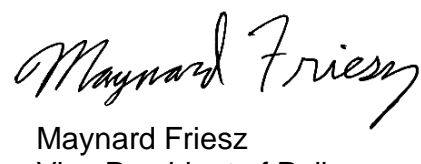
Sincerely,



Kenneth Hobby
President



Mary Schroth, M.D.
Chief Medical Officer



Maynard Friesz
Vice President of Policy