cure SMA Make today a breakthrough.

January 22, 2026

Dear Member of Congress:

On behalf of individuals and families affected by spinal muscular atrophy (SMA), a rare neuromuscular disease, **Cure SMA respectfully asks that you vote to finalize the medical research investments included in the Consolidated Appropriations Act of 2026**.

SMA is a debilitating disease that causes irreversible nerve damage and severe muscle loss, impairing a person's ability to walk, breathe, and perform daily activities. The disease affects children and adults in all 50 states. Cure SMA is the national organization advocating for research funding and policies that improve the lives of individuals with SMA and their families in your state and across the country.

The Consolidated Appropriations Act includes strong medical research investments at the U.S. Department of Defense (Division A) and the National Institutes of Health (Division B). These investments will help maintain the United States' global leadership in medical innovation, including the development of effective treatments and cures for chronic health conditions and rare diseases such as SMA.

The legislation begins to reinvest in the U.S. Department of Defense's Congressionally Directed Medical Research Program (CDMRP), which experienced significant funding cuts in fiscal year 2025. CDMRP supports cutting-edge biomedical research that complements NIH research to address the health challenges facing military service members, veterans, their families, and all Americans. **Cure SMA is pleased that "spinal muscular atrophy" is named in the explanatory statement as a research topic priority within CDMRP's Peer Reviewed Medical Research Program**. This provision recognizes the unmet needs within the SMA community and helps ensure that U.S. researchers have the resources necessary to pursue promising SMA research. Cure SMA also supports the legislation's funding for the NIH, including report language supporting SMA research at the National Institute of Neurological Disorders and Stroke.

We respectfully ask that you support the medical research investments included in the Consolidated Appropriations Act of 2026. Past federal investments have helped lead to effective treatments in SMA. The research proposed in Divisions A and B of this legislation will help build upon past research success to address the pressing needs of individuals with SMA and other chronic conditions. Cure SMA is also pleased that the legislation extends the U.S. Food and Drug Administration's Rare Pediatric Disease Priority Review Voucher (PRV) Program through September 30, 2020. The PRV Program has helped to incentivize research and development in rare diseases, including SMA. Thank you for your consideration. Your staff can reach out to Cure SMA through Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at 202-871-8004 or maynard.friesz@curesma.org.

Sincerely,

K.A.Hobby
Kenneth Hobby
President

Maynard Friesz
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Vice President of Policy