

November 13, 2025

Dear Member of Congress:

With the federal government reopening and Congress returning to regular business, Cure SMA urges you to prioritize the everyday living needs and advocacy priorities of individuals with spinal muscular atrophy (SMA) and their families. Cure SMA and the SMA community seek your support for new federal research in SMA, expanded healthcare access, and greater financial independence for people with disabilities.

SMA is a debilitating neuromuscular 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 individuals with SMA and their families in your state and across the country.

Please use your influential position in Congress to help advance the following SMA community priorities before the end of 2025:

Support New Federal Research in Spinal Muscular Atrophy

Past federal research in SMA has led to three effective U.S. Food and Drug Administration (FDA)-approved treatments. However, significant unmet need remains, particularly for older children and adults with SMA who lost motor function and muscle strength before receiving treatment. Both the U.S. House and U.S. Senate have taken important steps to address the chronic health and everyday living challenges faced by individuals with SMA. On July 31, the U.S. Senate Appropriations Committee approved SMA as a peer-reviewed medical research priority within the fiscal year (FY) 2026 Defense Appropriations Act.ⁱ The U.S. House Appropriations Committee also approved report language supporting new SMA research at the National Institutes of Health (NIH).ⁱⁱ

- **CURE SMA REQUEST: Finalize the FY 2026 Defense and Labor, HHS, Education Appropriations bills with the SMA research provisions** included in each bill's report. In addition, Cure SMA urges full funding for NIH programs and no less than \$370 million for the U.S. Department of Defense's Peer Reviewed Medical Research Program. *"I remain hopeful that with focused and sustained investment, we can reach a future where people like me regain physical abilities once thought to be permanently lost,"* said an **adult with SMA** who uses a power wheelchair and relies on caregivers for daily activities.

Promote Access to Affordable Healthcare and Specialized Care

Access to affordable healthcare and specialized care is essential for children and adults with SMA, who often experience complex medical needs due to disease-related complications. Individuals with SMA rely on health insurance to access treatments, therapies, medical devices, and specialized care. While most receive coverage through employer- or government-sponsored programs such as Medicaid and Medicare, some adults and families with SMA access care through the healthcare marketplace.ⁱⁱⁱ These individuals could face higher healthcare costs if the enhanced premium tax credits are not extended. In addition, due to the medically complex nature of SMA, individuals with SMA often require care from pediatric

neurologists, pulmonologists, and other neuromuscular disease specialists with expertise in SMA. For some individuals with SMA, the specialized care they need is only available across state lines, which can create an access barrier due to burdensome healthcare rules.

CURE SMA REQUEST: Improve healthcare affordability and accessibility for people with SMA and their families. Cure SMA urges Congress to extend the enhanced premium healthcare tax credits to ensure affordable coverage. We also ask that Congress streamline out-of-state provider enrollment in Medicaid, as proposed in the Accelerating Kids' Access to Care Act (S. 752 / H.R. 1509), to help children with SMA and other chronic conditions access the specialists they need. A **mother of a child with SMA** said, *"We live in a rural area with limited access to specialized care, especially in the case of a newborn baby like our son was when he was diagnosed. Please continue to fund access to healthcare."*

Promote Employment, Financial Security, and Rights for People with Disabilities

Because of debilitating symptoms caused by SMA, many individuals with SMA rely on the Supplemental Security Income (SSI) program to meet basic needs such as food and housing. Under current law, individuals receiving SSI may not have more than \$2,000 in assets to remain eligible; couples are limited to only \$3,000. Exceeding these asset limits by even one dollar can result in loss of SSI benefits and, in some cases, Medicaid services tied to SSI eligibility. These SSI asset limits, which have not been updated since 1989, discourages people with disabilities, including SMA, from working, marrying, and saving for their futures, as highlighted in a September 9 U.S. House Ways and Means Committee hearing.^{iv} Bipartisan legislation introduced in both chambers called the SSI Savings Penalty Elimination Act (H.R. 2540/ S. 1234) would raise asset limits and promote employment, financial security, and independence for people with disabilities.

- **CURE SMA REQUEST: Pass or include the SSI Savings Penalty Elimination Act in end-of-year legislative packages.** "Having the ability to be employed gives me a sense of independence that I normally don't have in my day-to-day life. But because of the fear of losing my health insurance and being unable to financially survive, I often turn down employment," said an **adult with SMA** who supports removing restrictions on people with disabilities.

People with SMA and disabilities rely on federal programs and policies to help them live healthy, independent, and productive lives. Cure SMA respectfully asks that you prioritize action on the issues above to remove barriers and improve the lives of people with 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,



Kenneth Hobby
President



Maynard Friesz
Vice President of Policy

ⁱ FY 2026 Defense Appropriations Report, <https://www.congress.gov/119/crpt/srpt52/CRPT-119srpt52.pdf#page=218>

ⁱⁱ FY 2026 Labor, Health and Human Services, and Education Appropriations Report, <https://www.congress.gov/119/crpt/hrpt271/CRPT-119hrpt271.pdf#page=108>

ⁱⁱⁱ Cure SMA State of SMA Report, https://www.curesma.org/wp-content/uploads/2025/04/State-of-SMA-Report2024_vWeb.pdf#page=30

^{iv} U.S. House Ways and Means Hearing on Removing Barriers to Work and Supporting Opportunity for Individuals with Disabilities, <https://waysandmeans.house.gov/event/joint-social-security-and-work-welfare-subcommittee-hearing-on-untapped-talent-in-america-removing-barriers-to-work-and-supporting-opportunity-for-individuals-with-disabilities/>