



Make today a breakthrough.

January 21, 2025

Re: Cure SMA Advocacy Agenda and Tax Priorities for the 119th Congress

Dear Member of Congress:

Cure SMA, which represents individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), is pleased to share the SMA community advocacy agenda for the 119th Congress. As you begin this new session of Congress, **we respectfully urge you to help implement SMA community priorities through upcoming tax, appropriations, and other legislative vehicles.**

SMA is a progressive neurodegenerative disease that attacks the nervous system and destroys muscles used for everyday living activities, such as walking, eating, and breathing. SMA impacts 1 in 15,000 births in the United States and approximately 1 in 50 residents of your state is a genetic carrier for SMA. If both parents are SMA carriers, every child they have together has a 25% chance of being diagnosed with SMA.

Past congressional policies and investments have led to the three FDA-approved SMA treatments and improvements to accessibility and community living. However, children and adults with SMA continue to face significant unmet needs and physical and systemic barriers that negatively impact their care, independence, and financial security. Our legislative agenda reflects these everyday living needs and challenges faced by individuals with SMA and their families. This year's top legislative priorities include:

- ***Investing in new research in SMA within the U.S. Department of Defense Peer-Reviewed Medical Research Program***
- ***Increasing access to paid caregiving services by strengthening Medicaid Home and Community-based Services***
- ***Promoting financial independence and the rights of individuals with SMA, including ending the disability marriage penalty***
- ***Implementing and enforcing the accessible air travel provisions in the recent FAA Reauthorization Act (P.L. 118-63)***

Cure SMA recognizes that early opportunities for Congress to act on behalf of the SMA community could be through tax-related legislation. As such, we actively seek your support for the following tax-related provisions to help advance the above SMA community agenda:

- **Caregiving:** Cure SMA supports efforts to offset long-term care expenses for family caregivers through a refundable federal tax credit (*as proposed in the Credit for Caring Act*)
- **Financial Independence:** Cure SMA supports efforts to promote financial independence by increasing the asset limits (which eliminates the disability marriage penalty) within the Supplemental Security Income program (*as proposed in the SSI Savings Elimination Act*)

- **Financial Independence (cont.):** In addition, Cure SMA supports efforts to further promote financial security for individuals with disabilities by strengthening the ABLE Program by:
 - Making permanent the ABLE to Work provision that allows individuals with SMA and other disabilities who work and earn income to contribute above the traditional ABLE account limits (*as proposed in the ENABLE Act & ABLE Tomorrow Act*)
 - Making permanent the ABLE program provision that allows 529 education account funds to be rolled over into an ABLE account without a tax penalty (*as proposed in the ENABLE Act & ABLE Tomorrow Act*)
 - Allowing employers to contribute to employees' ABLE accounts without the contribution counting against the person with disability's eligibility for government services or considered as taxable income (*as proposed in the ABLE Tomorrow Act*)
- **Employment:** Cure SMA supports efforts to expand the Work Opportunity Tax Credit (WOTC) for businesses who hire people with SMA and other disabilities (*as proposed in the Disability Employment Incentive Act*)
- **Accessibility:** Cure SMA supports efforts to increase accessibility for people with SMA and other disabilities in their personal and professional lives by:
 - Allowing homeowners to offset costs to make their home accessible for an individual with disabilities (*as proposed in the Home Accessibility Tax Credit Act*)
 - Expanding the Architectural and Transportation Barrier Tax Credit for businesses that make their business facilities or vehicles accessible (*as proposed in the Disability Employment Incentive Act*)
 - Increasing the Disability Access Expenditures Tax Credit for small businesses for the cost to increase accessibility for customers and workers with disabilities (*as proposed in the Disability Employment Incentive Act*)

Cure SMA and the SMA community look forward to working with you during the 119th Congress to help advance the priorities of the SMA community, whether through tax legislation, appropriations bills, or other legislative vehicles. If you have questions related to the SMA community agenda, your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA at maynard.friesz@curesma.org or 202-871-8004.

Sincerely,



Kenneth Hobby
President



Maynard Friesz
Vice President of Policy & Advocacy