



Make today a breakthrough.

July 12, 2023

The Honorable Sherrod Brown  
United States Senate  
Washington DC 20510

The Honorable Bill Cassidy  
United States Senate  
Washington DC 20510

The Honorable Brian Fitzpatrick  
United States House of Representatives  
Washington DC 20515

The Honorable Brian Higgins  
United States House of Representatives  
Washington DC 20515

Dear Senators Brown and Cassidy and Representatives Fitzpatrick and Higgins,

As the leading national organization that represents individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), **Cure SMA is pleased to support the Supplemental Security Income (SSI) Savings Penalty Elimination Act. Your bipartisan legislation will make it possible for individuals with SMA and other SSI beneficiaries to save for emergencies and their futures by increasing the program's asset limits.**

SMA is a progressive neurodegenerative disease that robs individuals of physical strength and impacts their ability to walk, eat independently, and perform other essential functions of everyday life. Some individuals with SMA rely on SSI for basic living needs such as food, clothing, and shelter. *"This support is my daughter's lifeline as she has SMA Type 1 and requires 24/7 care in order to fully participate in all that life has to offer her,"* said a **parent of an adult child with SMA**. In many states, SSI eligibility also provides access to personal care attendants and other Medicaid in-home services to assist with daily activities such as showering, dressing, and wheelchair transfers.

**SSI is an essential program that must be updated to meet the needs and financial independence of the people it serves.** SSI asset limits of \$2,000 for an individual and \$3,000 for couples are unreasonably low, making it difficult for individuals with disabilities to save for their futures. *"It is impossible to be able to save for any emergencies that may come up, such as car repair, broken appliances, or even for retirement in the future for people that can partially work,"* said a **California woman with SMA**. Last updated more than three decades ago, SSI asset limits also penalize individuals who marry by lowering the amount of assets beneficiaries can jointly have on hand. *"When we got married, our combined resources were just over the \$3,000 limit for married couples, and we lost our SSI for a month,"* said an **Ohio woman with SMA**. *"Luckily, we corrected that problem and were reinstated in the program. But the low married asset limit makes it impossible to save for a home or to be financially prepared for an emergency vehicle repair, which can be extremely expensive."*

**The Savings Penalty Elimination Act would make long-overdue improvements to SSI by increasing the asset limits to better reflect today's costs and needs of individuals with disabilities.** Your bipartisan legislation would increase the SSI asset limits to \$10,000 for



individuals and \$20,000 for couples and index the new limits to keep up with inflation. These important steps will encourage savings and provide a pathway for a stronger future. *“An increase in SSI asset limit would allow me to save more and be able to afford better safer housing,”* said **an adult with SMA.**

Cure SMA appreciates your leadership and efforts to promote the financial independence and independent living of people with SMA and other disabilities. The SMA community stands ready to help you pass this important legislation in the 118th Congress. Your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at 202-871-8004 or [maynard.friesz@curesma.org](mailto:maynard.friesz@curesma.org) if they have questions or need additional information.

Sincerely,

A handwritten signature in black ink that reads "K. A. Hobby".

Kenneth Hobby  
President  
Cure SMA

A handwritten signature in black ink that reads "Maynard Friesz".

Maynard Friesz  
Vice President of Policy  
Cure SMA