cure SMA

Make today a breakthrough.

March 24, 2025

The Honorable Catherine Cortez Masto
United States Senate
520 Hart Senate Office Building
Washington DC 20510

The Honorable Bill Cassidy
United States Senate
455 Dirksen Senate Office Building
Washington DC 20510

The Honorable Danny Davis
United States House of Representatives
2159 Rayburn House Office Building
Washington, DC 20515

The Honorable Brian Fitzpatrick
United States House of Representatives
271 Cannon House Office Building
Washington, DC 20515

Dear Senators Cortez Masto and Cassidy and Representatives Davis and Fitzpatrick,

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individuals with SMA and other SSI beneficiaries to save for emergencies and their futures by increasing the program's outdated asset limits.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. Many individuals with SMA rely on SSI for basic living needs such as food, clothing, and shelter. 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. *"Without caregivers and caregiving hours, I would not be able to live independently, be successfully employed, or enjoy anything fun as I would be stuck at home in bed,"* said an **Illinois woman with SMA**.

The current SSI asset limits of $2,000 for individuals and $3,000 for couples are outdated. *"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 an **adult with SMA**. These limits penalize people with disabilities for saving for emergencies and unfairly punish those who choose to get married. *"I was forced to choose between love and a future with the man that I loved or the security and independence that caregivers have provided my entire life,"* shared a **woman with SMA**.

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. As one **adult with SMA from Louisiana** explained, "*The current system makes it extremely difficult to meet all of my needs."* Your bipartisan legislation would allow individuals with SMA and other disabilities to save for emergencies and plan for their futures without fear of losing the support they rely on by increasing the asset limit to $10,000 for individuals and $20,000 for couples and index the new limits to keep up with inflation. As **a parent of an adult with SMA from Pennsylvania** put it, *"An increase in SSI asset limit would allow my daughter to save more and one day live independently*."

Cure SMA appreciates your leadership and commitment to promoting the financial independence and well-being of people with disabilities. The SMA community stands ready to support your efforts to pass this vital legislation in the 119th Congress. Your staff can contact Sarah Bellish, Manager of Policy and Advocacy at Cure SMA, at 202-871-8005 or sarah.bellish@curesma.org if they have any questions or need additional information.

Sincerely,

Maynard Friesz
Vice President of Policy & Advocacy
Cure SMA

Sarah Bellish

Sarah Bellish
Manager, Policy & Advocacy
Cure SMA