



Make today a breakthrough.

May 11, 2022

The Honorable Sherrod Brown
United States Senate
503 Hart Senate Office Building
Washington DC 20510

The Honorable Rob Portman
United States Senate
448 Russell Senate Office Building
Washington DC 20510

Dear Senators Brown and Portman,

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 (S. 4102). Your bipartisan legislation would allow individuals with SMA and other SSI beneficiaries to save for emergencies and the future by increasing the program's asset limits.**

SMA is a progressive neurodegenerative disease that robs individuals of their physical strength. Some individuals with SMA rely on SSI for their 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 ensures access to Medicaid healthcare and in-home supports, such as personal care attendants, that individuals with SMA may need to assist with daily activities such as showering, dressing, and wheelchair transfers.

The current SSI program includes unreasonably low asset limits that have not been updated in more than three decades. These strict caps, \$2,000 limit for individuals and \$3,000 limit for couples, leave individuals with SMA and others in the program unprepared to address financial emergencies or save for their futures. Individuals who exceed the SSI caps also risk losing their Medicaid care and supports, which allows them to remain independent in their community. *"I constantly worry if I'm making too much money, and alternatively, how I'm going to make ends meet. It's a confusing dynamic that makes zero sense. I'm penalized for working, but also not given the resources to be able to afford to live in this economy,"* said a young woman with SMA.

The Savings Penalty Elimination Act would make long-overdue improvements to help ensure SSI better meets the needs of today's beneficiaries. S. 4102 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.

Cure SMA fully supports the legislation and efforts to include the asset limit increase in the first available legislative vehicle, such as SECURE 2.0. Please do not hesitate to contact Cure SMA if you have any questions. Your staff can contact 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