



Make today a breakthrough.

June 8, 2021

The Honorable Sherrod Brown
United States Senate
503 Hart Senate Office Building
Washington DC 20510-3503

The Honorable Raúl M. Grijalva
United States House of Representatives
1511 Longworth House Office Building
Washington DC 20515

Dear Senator Brown and Representative Grijalva:

As the leading national organization that supports and advocates for individuals with spinal muscular atrophy (SMA), a genetic neuromuscular disease, **Cure SMA is pleased to support your Supplemental Security Income (SSI) Restoration Act that updates and restores fairness in SSI, a federal program that some people with SMA and other disabilities rely on for their basic living needs, such as food and shelter.**

SMA is a progressive neurodegenerative disease that robs individuals of physical strength, taking away their ability to walk, eat, and breathe. SMA impacts 1 in 11,000 births in the United States and approximately 1 in 50 people 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, regardless of race, ethnicity, and gender.

The SSI program was created in 1972 so that older adults over 65 and individuals with significant disabilities would “*no longer have to subsist on below-poverty-level incomes.*”ⁱ Unfortunately, today’s maximum monthly SSI benefit of [\\$794](#) per individual is well under the federal poverty level of \$1,073 per month.ⁱⁱ In addition, the program still uses income and asset limits set in 1989ⁱⁱⁱ and reduces benefit levels if the SSI recipient receives rent, groceries, or other in-kind assistance^{iv} or is married to another SSI beneficiary.^v These provisions fail to reflect the needs of today’s beneficiaries. In addition, updating the asset limit and other thresholds will benefit non-SSI beneficiaries, including individuals with SMA, given the SSI guidelines can impact certain eligibility for Medicaid home and community-based services, such as personal care attendants or home health aides.^{vi}

The SSI Restoration Act would update and improve SSI by aligning the benefit amount to the federal poverty level, raising the asset limit, excluding retirement accounts from the asset calculation, and eliminating marriage penalties and in-kind support and maintenance provisions. The improvements included in your legislation will help improve the financial security of people with disabilities who live in poverty at more than twice the rate of people without disabilities.^{vii} Adults with SMA identified financial security as one of their top priority areas for the 117th Congress.



Cure SMA strongly supports the SSI Restoration Act. We look forward to working with you to enact these important provisions into law as quickly as possible, whether through passage of the legislation or through inclusion in an upcoming recovery package bill. For more information, 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,

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

Kenneth Hobby
President

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

Maynard Friesz
Vice President of Policy & Advocacy

ⁱ Amendments to the Social Security Supplemental Security Income for the Aged, Blind, and Disabled [Committee Report](#), 1972
ⁱⁱ [SSI Federal Payment Amounts For 2021](#), Social Security Administration, 2021
ⁱⁱⁱ [SPOTLIGHT ON RESOURCES -- 2021 Edition](#), Social Security Administration, 2021
^{iv} [In-kind Support and Maintenance](#), Social Security Administration, 2021
^v [Treatment of Married Couples in the SSI Program](#), Social Security Administration, 2021
^{vi} [Medicaid Eligibility: Older Adults and Individuals with Disabilities](#), Congressional Research Service, 2019
^{vii} [National Council of Disabilities Report](#), 2017