



Make today a breakthrough.

June 24, 2022

The Honorable Ron Wyden
Chairman
Senate Finance Committee
United States Senate
Washington DC 20510

The Honorable Sherrod Brown
Member, Senate Finance Committee
United States Senate
Washington DC 20510

The Honorable Rob Portman
Member, Senate Finance Committee
United States Senate
Washington DC 20510

Dear Senators Wyden, Brown, and Portman,

Thank you for your commitment during the June 22 Finance Committee executive session markup to increase the asset limit within the Supplemental Security Income (SSI) program by the end of the year. Making this long overdue change will greatly improve the independence and financial security of individuals living with spinal muscular atrophy (SMA) and others who rely on SSI for their basic living needs.

SMA is a neurodegenerative disease that robs individuals of physical strength, impacting their ability to walk, eat, and breathe. Individuals with SMA who are enrolled in SSI highlight the challenge they face under current asset limit rules.

- *“SMA is an extremely difficult condition in terms of physical hardships and to have a financial hardship added to persons with SMA is inappropriate,”* said a **woman with SMA**.
- *“\$2000 is not a lot of money. With this requirement, SSI becomes a solitary source of income as opposed to supplemental, preventing those with difficulty to work full time or pursue financially rewarding careers, the opportunity to save, or make smart investing decisions for their future,”* said a **man with SMA**.
- *“Those with disabilities should not have to choose between essential medical services and the ability to save for emergencies, particularly when we all know there are so many uncovered additional costs for those with disabilities,”* said a **woman with SMA**.



Cure SMA, which represents individuals with SMA and their families across the country, including those who rely on SSI, appreciate your leadership on this issue and your sponsorship of the SSI Savings Penalty Elimination Act (S.4102). While we were disappointed that the asset limit increase fell outside the scope of the retirement savings legislation being considered at the markup, we were heartened by the SSI discussion and the commitment by each of you to raise the SSI asset limits by the end of the year.

Cure SMA and our supporters greatly appreciate the efforts of you and your staff to help update this outdated provision. Please let us know how we can assist you in your efforts to raise the SSI asset limits by the end of 2022. 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.

Thank you for considering the views of the SMA community.

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