



Make today a breakthrough.

June 15, 2022

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

The Honorable Mike Crapo
Ranking Member
U.S. Senate Finance Committee
United States Senate
Washington DC 20510

Dear Chairman Wyden and Ranking Member Crapo,

Recently, you have heard from individuals with spinal muscular atrophy (SMA) and their families about two disability-related legislative proposals that would allow people with SMA and other disabilities to save for their futures and improve their economic self-sufficiency. As you prepare for a markup of retirement security legislation (SECURE 2.0), **Cure SMA asks that you include these two bipartisan bills, Supplemental Security Income (SSI) Savings Penalty Elimination Act and the ABLE Age Adjustment Act, in the base SECURE 2.0 legislation.**

SMA is a neurodegenerative disease that robs individuals of physical strength, impacting their ability to walk, eat, and breathe. Some individuals with SMA rely on SSI for their basic living needs, such as food, clothing, and shelter, and for access to Medicaid and its in-home supports. In addition, some individuals with SMA utilize ABLE accounts to help save for future expenses, such as housing, transportation, and health care, without jeopardizing their eligibility for Medicaid and other essential services. **Both the SSI and ABLE programs require updates to encourage greater savings and to promote independence of individuals with SMA and other disabilities.**

The **SSI Savings Penalty Elimination Act (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. The current SSI asset 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 that helps them 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 **ABLE Age Adjustment Act (S.331)** would expand the number of individuals with disabilities eligible to open an ABLE account, which is currently only available to individuals whose disability onset occurred before age 26. The ABLE Age Adjustment Act would increase the eligibility age to include all individuals with disabilities whose age of disability onset occurs prior to age 46. This change could benefit a segment of the SMA population where SMA symptoms only occur after 35 years of age (SMA Type 4). This change will strengthen and make the ABLE program fairer by increasing the pool of possible ABLE account holders.



These bipartisan bills have wide support from the SMA and disability communities as well as key Finance Committee Members. On behalf of children and adults with SMA and their families, we respectfully ask that you use your influential position on the Finance Committee to ensure these bipartisan provisions are included in the based SECURE 2.0 bill being considered by the committee. 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