



Make today a breakthrough.

June 17, 2024

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,

As you consider challenges and opportunities related to work and Social Security benefits in your upcoming Finance Committee hearing, Cure SMA is pleased to share the perspective of individuals with spinal muscular atrophy (SMA) who are impacted by a Social Security policy that disincentivizes work and financial independence. **Cure SMA and the SMA community respectfully ask that you consider raising the asset limit within the Supplemental Security Income (SSI) as proposed in the bipartisan, bicameral SSI Savings Penalty Elimination Act (S. 2767).**

Cure SMA is the national organization that represents individuals with SMA, a progressive neurodegenerative disease that attacks nerve cells and causes debilitating muscle weakness and severe motor function loss. Many individuals with SMA rely on SSI for their basic living needs and Medicaid for caregivers services to assist with daily activities. *"My daughter requires 24/7 care in order to fully participate in life,"* said a **parent of an adult child with SMA** who described the SSI benefit as *"my daughter's lifeline."*

While disease severity limits the ability of many SSI beneficiaries with SMA from working, other individuals with SMA who can work either work part-time or don't work at all for fear of losing their benefits, especially their SSI-connected caregiving services through Medicaid. According to Cure SMA's 2024 *Stuck Inside* [caregiving report](#), individuals with SMA require, on average, 100 or more caregiving hours a week to assist with wheelchair transfers, bathroom support, and household duties, such as laundry, shopping, and light housekeeping. *"I depend on caregiving for almost all activities of daily living,"* said an **adult with SMA**.

Despite work incentives such as Social Security's Ticket to Work Program, individuals with SMA and other disabilities who receive SSI remain concerned about how work-related earnings and savings will impact their ability to retain their essential benefits. Ticket to Work allows SSI beneficiaries who are interested in working to try it without consequences through a trial work period. After this trial period, an individual's SSI benefit will be modified based on their earnings until they earn enough to transition off SSI. However, these working individuals with SMA and other disabilities still require Medicaid caregiving services to live and to participate in the workforce. In order to retain these essential services, they must meet all other [requirements for SSI eligibility](#), including the very low, 40-year-old asset limits of \$2,000 for an individual or \$3,000 for a couple. *"Imagine having to keep your savings at \$2,000 or be at risk at being cut off from essential needs, such as Medicaid,"* said an **adult with SMA**. Unfortunately, this is the



reality for individuals with SMA and other disabilities. The result is that many individuals with SMA who want to work decide against it for fear of losing their independence or work only part-time to avoid going over the limits. Overall, 27 percent of adults with SMA said they do not work or work only part-time to maintain their disability benefit eligibility.

**The SMA community is united in its support for addressing the outdated SSI law.** Adults with SMA, parents of children with SMA, and other Cure SMA supporters sent in more than 600,000 messages into Congress in support of the SSI Savings Penalty Elimination Act (S. 2767 & H.R. 5408), including more than 309,000 from Finance Committee member state constituents. Supporters include **individuals with SMA** (*"I have SMA and this cap is hugely debilitating, it prevents me from saving money and pursuing employment as I would lose benefits necessary for my health"*), **parents** (*"I have two children with SMA and the SSI asset limits are ridiculously low meant to keep us poor"*), **grandparents** (*"my grandson has spinal muscular atrophy. Please support him and our SMA community"*), **aunts and uncles** (*"My niece has SMA Type 1, so this cause is near and dear to my heart, and is very important to me and my family"*), **siblings** (*"as the sister of two brothers who have SMA, I ask that you support the SSI Savings Penalty Elimination Act"*) and other **supporters** (*"I have friends who have SMA and related disabilities and I know how hard it is for them to live with their conditions on top of worrying about financial security and issues. This legislation would ease their anxieties about things like bills or emergencies and make their lives easier"*). **Together, the SMA community urges the Finance Committee to help increase the asset limit before the end of Congress.**

Thank you for holding a hearing on work and Social Security benefits and for considering the views of the SMA community. 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](mailto:maynard.friesz@curesma.org).

Sincerely,

Kenneth Hobby  
President

Maynard Friesz  
Vice President of Policy