



Make today a breakthrough.

May 25, 2022

The Honorable Joyce Beatty
Chairwoman
Subcommittee on Diversity and Inclusion
House Financial Services Committee
United States House of Representatives
Washington DC 20515

Anthony Gonzalez
Vice Ranking Member
Subcommittee on Diversity and Inclusion
House Financial Services Committee
United States House of Representatives
Washington DC 20515

Dear Chairwoman Beatty and Vice Ranking Member Gonzalez,

On behalf of individuals with spinal muscular atrophy (SMA), a neurodegenerative disease that impacts the muscles used for breathing, walking, and other activities, **Cure SMA thanks you for holding a hearing focused on barriers people with SMA and other disabilities face related to economic inclusion and security.** We ask that you help address the challenges raised at your hearing by supporting Cure SMA priorities to eliminate the savings penalty, incentivize employment, and expand accessible and affordable housing and transportation options.

ELIMINATING THE SAVINGS PENALTY

Some individuals with SMA rely on the Supplemental Security Income (SSI) program to assist with their basic living needs such as food, clothing, and shelter. In some states, SSI eligibility also provides critical access to specialized healthcare and community living supports through Medicaid. SSI is long overdue for an update to better reflect today's living costs and the needs of individuals with disabilities in the program.

While we support broad SSI program improvements, including benefit increases and removing the marriage penalty, **Cure SMA urges Congress to support the solution raised at your hearing to boost SSI's extremely low asset limits, as proposed in the bipartisan SSI Savings Penalty Elimination Act.** *"These outdated caps severely limit my ability to save for emergencies or the future,"* said an adult woman with SMA. A parent of a college student with SMA said, *"having more savings would help my daughter as she graduates and tries to live as independently as possible."*

INCENTIVIZE EMPLOYMENT

Like other individuals with disabilities, some adults with SMA also struggle to find employment, even though individuals with SMA are highly qualified and educated, with 22% having earned a bachelor's degree and 20% completing a master's degree. According to Cure SMA's 2021 Community Survey, 23% of adults with SMA who sought employment were unemployed and 15% of those who were employed part-time sought full-time work. *"We bring so much to the workforce. Not all employers see our value,"* said an employed adult man with SMA. *"They don't realize that we are way more creative and more adaptable and can be a valuable asset to the company because of all the adversity we face in our lives."*



Cure SMA urges Congress to help breakdown workplace barriers for individuals with SMA and other disabilities by supporting the bipartisan Disability Employment Incentive Act (H.R.3765), which expands existing tax credits to encourage hiring and to make workplaces more accessible. In addition, Cure SMA seeks robust funding for the Vocational Rehabilitation Program, a Department of Education program that funds job training and employment services for people with disabilities, including those with SMA.

INVEST IN AFFORDABLE AND ACCESSIBLE HOUSING AND TRANSPORTATION

Physical and economic barriers in housing and transportation continue to jeopardize the full independence and community living of individuals with SMA and other disabilities. More than three decades since the passage of the Americans with Disabilities Act, individuals with SMA who use power wheelchairs still struggle to find affordable, accessible, and workable housing units and transportation modes. An adult with SMA found that driving his power wheelchair in the bike lane 45 minutes to and from work was his fastest and most reliable transportation option rather than public transportation. A woman with SMA described the challenge of finding accessible housing in her community. *“I make enough money to be able to live in a safe apartment in my city, but not an accessible one. But the accessible housing units have income limits that impact whether I can advance financially in my career without losing housing stability.”*

Cure SMA urges Congress to address the lack of affordable and accessible housing and transportation by supporting funding increases in the fiscal year 2023 Transportation, and Housing and Urban Development, and Related Agencies Appropriations bill for Section 811 Supportive Housing for People with Disabilities Program and for Enhanced Mobility of Seniors and Individuals with Disabilities. Specifically, we seek no less than \$287.7 million for Section 811, as requested in the Department of Housing and Urban Development’s FY 2023 budget justification, and \$50 million for Formula Grants for the Enhanced Mobility of Seniors and Individuals with Disabilities, as requested in the Department of Transportation’s FY 2023 budget justification.

Thank you for holding this important hearing and for your consideration of Cure SMA’s requests to help alleviate the economic security challenges faced by people with SMA and other disabilities. 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,

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Cure SMA

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