cure SMA

Make today a breakthrough.

September 24, 2021

The Honorable Sherrod Brown
Chairman
Subcommittee on Social Security, Pensions, and Family Policy
United States Senate
Washington DC 20510

The Honorable Todd Young
Ranking Member
Subcommittee on Social Security, Pensions, and Family Policy
United States Senate
Washington DC 20510

Dear Chairman Brown and Ranking Member Young,

As the leading national organization that represents individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), **Cure SMA applauds your leadership in holding a hearing to discuss ways to update and improve the Supplemental Security Income (SSI) program.** Cure SMA supports SSI changes discussed during your hearing to better meet the needs of individuals with SMA and others who benefit from the program, including increasing the asset limit, removing the marriage and in-kind support penalties, and strengthening the voluntary transition to work while maintaining essential healthcare.

SMA is a progressive neurodegenerative disease that affects the motor nerve cells in the spinal cord, impeding a person's ability to walk, swallow, and, in the most severe cases, to breathe. SMA does not, however, affect a person's ability to think, learn, and build relationships.

For some individuals with SMA, SSI is a vital lifeline in assisting with basic living needs such as food, clothing, and shelter. SSI is also key to accessing healthcare and long-term services and supports, given SSI beneficiaries in many states are automatically eligible for Medicaid. Individuals with SMA may require intensive medical care and specialized equipment and utilize personal care attendants to assist with their activities of daily living, such as showering, dressing, transferring to a power wheelchair or other mobility device, and assisting with bathroom breaks.

A ***36-year-old Mississippi man with SMA Type 2*** relied on SSI for several years, including while he lived independently in college with the help of caregivers provided through Medicaid. After college, he faced two challenges in his goal of employment. One, he graduated during the 2008 recession with limited job prospects. Two, he was unsure how employment would impact his healthcare and other Medicaid-funded supports given unreasonably low asset and earning limits. *"There is definitely a flaw in the system when people face a detrimental effect on their healthcare and supports when they earn even a small amount of income."* In 2015, he was hired as a full-time web developer and no longer receives a monthly SSI cash benefit. However, he continues to face strict asset and income limits. *"Anytime I'm up for a promotion or a raise I worry if it will make me ineligible for my personal care attendant hours, which I need to maintain my employment. In addition, you cannot save assets in a financially responsible way because of the program limits."* **Cure SMA supports recommendations offered during your Finance Subcommittee hearing to remove or update SSI income and asset thresholds.**

In addition, SSI beneficiaries with SMA are negatively impacted by the SSI provisions that reduce the SSI benefit amount for married couples receiving SSI and for receiving in-kind support from family or friends, such as help with groceries or rent. *"These harsh regulations prevent me from being able to marry my partner as our joint finances would render my services inactive,"* said a ***35-year-old Minnesota woman with SMA Type 2.*** *"I can't articulate enough how dehumanizing these current laws are and how much my life would change for the better if they were restored."* **Cure SMA supports recommendations offered during your Finance Subcommittee hearing to eliminate the marriage penalty and in-kind support and maintenance provisions in SSI.**

On behalf of all individuals with SMA and their families, **Cure SMA thanks you for shining the spotlight on the need to improve the SSI program.** This important program needs to be updated to reflect the current needs of beneficiaries, including individuals with SMA. 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.

Sincerely,

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