Make today a breakthrough.

November 17, 2022

The Honorable Charles Schumer
Majority Leader
United States Senate
Washington, D.C. 20510

The Honorable Nancy Pelosi
Speaker
U.S. House of Representatives
Washington, DC 20515

The Honorable Mitch McConnell
Minority Leader
United States Senate
Washington, D.C. 20510

The Honorable Kevin McCarthy
Minority Leader
U.S. House of Representatives
Washington, D.C. 20515

Dear Senate Majority Leader Schumer, Senate Minority Leader McConnell, Speaker Pelosi, and House Minority Leader McCarthy,

On behalf of individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), **Cure SMA respectfully asks that you include important SMA community priorities in any end-of-session legislative packages being considered in Congress.** Specifically, we ask that you increase the asset limit within the Supplemental Security Income (SSI) program, finalize the fiscal year (FY) 2023 budget, including retaining the language related to SMA research, and expand eligibility for opening an ABLE disability account.

SMA is a neurodegenerative disease that affects the motor nerve cells in the spinal cord and impacts the muscles used for activities such as breathing, eating, crawling, and walking. SMA impacts 1 in 11,000 births in the U.S., and about 1 in every 50 Americans is a genetic carrier. Cure SMA represents children and adults with SMA and their families in all 50 states.

Cure SMA has advocated throughout the 117th Congress with and on behalf of the SMA community in support of legislation and federal programs that promote greater independence for children and adults with SMA. The 117th Congress has an opportunity to greatly impact the SMA community by including the following priorities in any final legislative packages:

- **Increasing the SSI Asset Limit:** Many individuals with SMA rely on SSI for their basic living needs, such as food, clothing, and shelter. In many states, SSI eligibility also allows an individual with SMA to access Medicaid in-home caregiving supports. Current SSI rules severely limit the ability of beneficiaries to prepare for short- and long-term financial emergencies. Beneficiaries must limit their countable assets to no more than $2,000 for individuals or $3,000 for married beneficiaries. These strict asset limits have not been updated in decades. Cure SMA supports a bipartisan effort (S.4102) to increase the SSI asset limits and ensure that the limits keep up with inflation. **Please increase the SSI asset limits before the end of the 117th Congress.**

- **Finalize the FY 2023 Funding Bills:** Many individuals with SMA utilize federal programs that are funded through the annual appropriations process. Cure SMA supports investments in research, employment, housing, transportation, technology, and the Social Security Administration. **Please finalize the FY 2023 funding bills and prioritize the following SMA community priorities:**

  - ***National Institutes of Health (NIH) SMA Research:*** The U.S. House and U.S. Senate Appropriations Committee included language in their Labor-HHS-Education Appropriations reports directing the NIH to build off its past SMA research success to address the unmet needs that still exist, particularly for adults with SMA. **Please retain this important report language in the final FY 2023 bill.**

  - ***Disability Program Funding:*** Key federal programs related to employment, housing, transportation, and technology help promote greater independence for individuals with SMA and other disabilities. **Please fully fund these key federal disability programs in the final FY 2023 bill**, including the Vocational Rehabilitation Program (Department of Education), Section 811 Housing for People with Disabilities (Department of Housing and Urban Development), Mobility for People with Disabilities and Older Adults (Department of Transportation), and Assistive Technology State Grants (Department of Health and Human Services).

  - ***Social Security Administration (SSA) Operating Expenses:*** Individuals with SMA and other disabilities regularly interact with SSA staff to determine and maintain eligibility for SSI and other SSA programs. Unfortunately, the SSA administrative budget has not kept up with inflation, putting a heavy strain on the agency's ability to meet demand and service quality. **Please fully fund the President's FY 2023 budget request for SSA to ensure that SSA can meet the needs of its beneficiaries, including those with SMA.**

- **Expand Eligibility for ABLE Disability Accounts**: In 2014, Congress created ABLE accounts to allow certain individuals with disabilities to save money in a tax-exempt account for future expenses, such as housing, transportation, and health care. ABLE accounts have greatly improved the financial well-being of many individuals with SMA and other disabilities while not jeopardizing their access to Medicaid and other key federal programs. The bipartisan ABLE Age Adjustment Act (S.331/ H.R. 1219), which was included in the U.S. Senate's retirement savings legislation, would increase the eligibility age to include all individuals with disabilities whose age of disability onset occurs prior to age 46. Current law limits ABLE accounts to those whose onset occurs before age 26. **Please approve the ABLE account eligibly expansion before the end of the 117th Congress.**

These actions cannot wait until the next Congress. Please use your influential leadership positions to finalize these important priorities of individuals with SMA and their families. Your staff can reach out to Cure SMA at maynard.friesz@curesma.org or 202-871-8004 if they have questions related to these SMA community priorities.

Thank you for your consideration

Sincerely,

Kenneth Hobby
President
Cure SMA