



November 10, 2022

The Honorable Nancy Pelosi
1236 Longworth House Office Building
Washington, D.C. 20515

The Honorable Kevin McCarthy
2468 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Chuck Schumer
322 Hart Senate Office Building
Washington, D.C. 20510

The Honorable Mitch McConnell
317 Russell Senate Office Building
Washington, D.C. 20510

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

On behalf of the approximately 300,000 Americans living with a neuromuscular disease, the undersigned patient advocacy organizations urge Congress to include two bills with broad bi-partisan support that will increase economic independence for Americans with neuromuscular diseases in any year-end omnibus package: the ABLE Age Adjustment Act (H.R. 1219/S. 331) and the SSI Savings Penalty Elimination Act (S. 4102).

Many in the neuromuscular disease community rely on ABLE accounts and Supplemental Security Income to meet their expenses. However, there are flaws in both programs that hinder the ability of people with disabilities to build savings for expenses like wheelchair repairs. Currently, SSI recipients have stringent asset limits that hinder their ability to save, get married, or participate in the workforce without jeopardizing their SSI benefits. Additionally, many people who get a diagnosis later in life are ineligible for an ABLE account.

ABLE accounts allow individuals who acquire a qualifying disability by age 26 to save money for specific, disability-related expenses not covered by insurance without jeopardizing their eligibility for Medicaid or other benefits like SSI. The ABLE Age Adjustment Act will increase the age by which individuals must have a qualifying disability from 26 to 46, which will expand the ability of people who get diagnosed with neuromuscular diseases like ALS, Charcot-Marie-Tooth disease, Pompe disease, and myotonic dystrophy after age 26 to use an ABLE account to save for disability-related expenses.

ABLE accounts are a lifeline for people with neuromuscular diseases who currently may not need Supplemental Security Income (SSI), Medicaid, or home and community-based services, but may need them in the future as their disease progresses. Increasing the age for ABLE accounts will allow individuals diagnosed with a disability after age 26 to maintain their freedom and independence by saving money for future disability-related expenses that Medicare, Medicaid, or SSI do not cover, including complex rehabilitation technology such as power wheelchairs.

Additionally, many individuals with neuromuscular diseases rely on Supplemental Security Income to pay their bills. To receive SSI benefits, recipients must adhere to strict asset limitations, which prohibit the possession of more than \$1,000 in assets for individuals or \$2,000 for a couple, limits that have not been updated since the 1980s. In addition, the current maximum benefit for SSI is only \$841. The SSI Savings Penalty Elimination Act (S. 4102) would raise these asset limits to \$10,000 for an individual and \$20,000 for a couple and allow individuals who rely on SSI to participate in the workforce if they so choose, save for a rainy day, or future expenses.

These bills have broad bipartisan support and will go a long way in enabling individuals with neuromuscular diseases to achieve economic independence by allowing them to save for the future, for disability-related expenses, or unexpected financial emergencies. We urge Congress to include these important priorities in any end of year legislative package.

If you have any questions or desire additional information, please do not hesitate to contact [Michael Lewis](mailto:mlewis@mdausa.org) at the Muscular Dystrophy Association at mlewis@mdausa.org or (540) 447-9438.

Sincerely,

Acid Maltase Deficiency Association
ALS Association
Answer ALS Foundation

Charcot-Marie-Tooth Association
CMT Research Foundation
Coalition to Cure Calpain 3
Cure CMD
CureDuchenne
CureLGMD2i
Cure Rare Disease
Cure SMA
Cure VCP Disease
Hereditary Neuropathy Foundation
Les Turner ALS Foundation
LGMD Awareness Foundation
MitoAction
Muscular Dystrophy Association
The Myositis Association
National Ataxia Foundation
Neuromuscular Disease Foundation
Parent Project Muscular Dystrophy
The Speak Foundation
Team Gleason
Team Titin
United Mitochondrial Disease Foundation

cc: Representative Richard Neal, Chairman, House Committee on Ways and Means
Representative Kevin Brady, Ranking Member, House Committee on Ways and Means
Senator Ron Wyden, Chairman, Senate Finance Committee
Senator Mike Crapo, Ranking Member, Senate Finance Committee