



## **Cosponsor the Alleviating Barriers for Caregivers Act (S. 1227/H.R. 2491)**

MDA advocates to reduce administrative burdens on family caregivers and supports the bipartisan *Alleviating Barriers for Caregivers Act* (“ABC Act”), to require the Centers for Medicare and Medicaid Services (CMS), Social Security Administration (SSA), and Children’s Health Insurance Program (CHIP) to review and simplify processes, procedures, forms, and communications to streamline benefits navigation for family caregivers.

### **Background on Neuromuscular Disease and Caregiving**

Neuromuscular diseases impact muscle function due to problems with the nerves or muscles. The spectrum of neuromuscular diseases is broad, with some occurring from birth and others appearing later in life.

Due to the progressive nature of neuromuscular diseases, many individuals will require assistance and support at some point in their journey. Family caregivers are the backbone of the neuromuscular care system, often helping to prevent unnecessary, costly, and harmful institutionalization.

### **Impact on Families Affected by Neuromuscular Diseases**

While caregiving can be rewarding, many family caregivers struggle to navigate confusing, burdensome administrative processes to get the support their loved ones need.

A top challenge the neuromuscular community reports to the MDA Resource Center are issues related to onerous paperwork to affirm and re-affirm eligibility for programs, including Medicaid, Medicare, and Social Security disability benefits.

The neuromuscular community experiences unique challenges with meeting agency paperwork requirements. Due to muscle weakness, there is limited ability to print documents, make photocopies, or go physically into offices for assistance. Many report challenges with not having calls returned or being unable to speak to staff familiar with their situation. This additional stress burden negatively impacts the wellbeing of family caregivers and individuals affected by neuromuscular disease.

### **Congressional Ask:**

**Co-sponsor the ABC Act, to require CMS and SSA – with input from family caregivers, including caregivers with disabilities, and individuals entitled to or filing for benefits – to review and simplify processes for tasks such as establishing eligibility, enrolling in/maintaining eligibility, and utilizing the full benefits available in Medicaid, Medicare, CHIP, SSI, and SSDI.**

### **What are neuromuscular diseases?**

- Neuromuscular diseases affect individuals’ muscles, limbs, and mobility.
- MDA is the #1 voluntary health organization in the U.S. for people living with muscular dystrophy, ALS, and related neuromuscular diseases. For 75 years, MDA has led the way in accelerating research, advancing care, and advocating for our families.
- Our mission is to empower the people we serve to live longer, more independent lives.

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