MDA® | Muscular Dystrophy Association

January 21st, 2026

The Honorable Mike Johnson
Speaker of the House
418 Cannon House Office Building
Washington, DC 20515

The Honorable Hakeem Jeffries
Minority Leader
2267 Rayburn House Office Building
Washington, DC 20515

Re: The Muscular Dystrophy Association Supports the Consolidated Appropriations Act of 2026 (H.R.7148)

Dear Speaker Johnson and Minority Leader Jeffries:

In service of the neuromuscular disease (NMD) patient community, the Muscular Dystrophy Association (MDA) supports the "Consolidated Appropriations Act of 2026 (H.R.7148) and urges all members of the House of Representatives to vote for the legislation when it comes up for a vote. In particular, we support the legislation's $48.7 billion of funding and accompanying policy for the National Institutes of Health (NIH), the inclusion of the Give Kids a Chance Act the Accelerating Kids Access to Care Act, and pharmacy benefit manager reforms, and the funding of critical programs across the Department of Health and Human Services and Congressionally Directed Medical Research Programs.

MDA is the #1 voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases. For over 75 years, MDA has led the way in accelerating research, advancing care, and advocating for the support of our community. MDA's mission is to empower the people we serve to live longer, more independent lives.

This legislation will increase the NIH's funding for the current fiscal year. While we continue to support larger increases to NIH's budget to fund lifechanging, sometimes lifesaving, medical research, we support this modest increase. Additionally, the agreement includes provisions that would discourage the NIH from moving forward with harmful funding policies, including flat funding of indirect cost coverage and the greater use of multi-year grants. Finally, the agreement includes the most robust funding for the ACT for ALS in the law's history, as well as increased funding for the Rare Disease Clinical Research Network.

The bill includes the Give Kids a Chance Act and the Accelerating Kids Access to Care Act, critical legislation for children with neuromuscular diseases. The Give Kids a Chance Act will extend the Rare Pediatric Disease Priority Review Voucher program, arguably the most important and impactful incentive for companies to develop treatments for rare pediatric neuromuscular conditions. The legislation also closes loopholes in the Orphan Drug Act. The Accelerating Kids Access to Care Act will facilitate the streamlining of enrollment for out-of-state providers in Medicaid programs to provide expert care to children with rare and complex medical conditions. The bill will also enact reforms to the practices of pharmacy benefit managers (PBMs), key players in the high cost of care for the neuromuscular disease community.

This bi-partisan agreement will fund the Centers for Disease Control and Prevention's muscular dystrophy research programs, ALS natural history study, and newborn screening programs at adequate levels, and funds the Health Resources and Services Administration's newborn screening programs at consistent levels. All of these programs are critical to the health and wellness of the neuromuscular disease community.

Finally, the legislation includes robust funding for neuromuscular disease research in the Congressionally Directed Medical Research Programs. In particular, the legislation includes $40 million in funding for ALS research, $12.5 million in funding for Duchenne muscular dystrophy, and includes myotonic dystrophy, spinal muscular atrophy, mitochondrial diseases, and facioscapulohumeral dystrophy in the Peer Reviewed Medical Research Program.

While each of these programs and initiatives deserve an increase in funding, we understand the time and environment in which this bipartisan agreement was struck. Consequently, while we anticipate supporting increases in appropriations for these programs going forward, we support this agreement and urge all members to vote yes.

We appreciate this opportunity to provide you with perspectives from the NMD community. For questions regarding MDA or the above comments, please contact Paul Melmeyer, Executive Vice President, Public Policy and Advocacy, at pmelmeyer@mdausa.org,

Sincerely,

Paul Melmeyer, MPP
Executive Vice President, Public Policy and Advocacy
Muscular Dystrophy Association