

Advocating for the MDA community

For 75 years, Muscular Dystrophy Association (MDA) has led the way in accelerating research, advancing care, and advocating for the support and inclusion of families living with neuromuscular disease. The NALC has been there for 73 of these years, raising money to help deliver a cure. During these years, MDA has been lobbying Congress to improve conditions for these families.

Every year, MDA partners with NALC branches across this great land to organize fundraisers. Proceeds from these entertaining events help families cope with MD and other neuromuscular disorders. In addition to “Delivering the Cure,” our mission is to provide comfort and hope to patients and caregivers. People go to amazing lengths to advance this cause daily, including dedicated medical specialists involved in patient care and treatment.

MDA provides a comprehensive program of services, including clinics at multiple hospitals, a summer camp for children ages 6 to 17, a “loan closet” with durable medical equipment, and millions of dollars in funding for neuromuscular disease research.

Just as NALC has a great legislative agenda to ensure that our letter carriers are treated fairly and given what they deserve through legislation, MDA does the same by advocating for better public policies to further MDA’s mission. And as we have tool kits to help our members understand the details, facts, sources and numbers of our agenda, so does MDA. It, too, has an action center where one can get up to date with all the current issues or find information on ways to help: mda.org/get-involved/advocacy.

The MDA Action Center is the advocacy page where you can learn more about policies and issues affecting the MDA community and about ways you can get involved. Every letter carrier is important to the cause; every MDA advocate is essential to progress. MDA welcomes everyone, and hopes that you will join in making a difference.

MDA is dedicated to advocating public policies and programs that empower children and adults with neuromuscular disease.

MDA’s advocacy pillars are for its patients to have access to care, to accelerate therapeutic development, and for patients to be empowered with independence. Below are the recent victories MDA secured in previous years.

Access to care:

- Expanded and invested in newborn screening
- Prescription drug affordability

- Telehealth flexibilities
- Investment in key government programs
- LGMD diagnostic codes
- Seat elevation systems

Accelerating therapeutic development:

- FDA and clinical trial reforms
- ACT for ALS implementation
- Research funding and investments

Empowerment and independence:

- ABLE Age Adjustment Act
- Accessible air travel

The MDA celebrated several legislative victories in 2024, including the FAA Reauthorization Act and the Accelerating Kids’ Access to Care Act.

FAA Reauthorization Act:

- It includes significant improvements in air travel accessibility.
- It requires training for airport and airline staff who assist passengers with disabilities.
- It creates a pathway for wheelchair spots on airplanes.
- It holds airlines responsible for reporting damage to wheelchairs.
- It gives the disability community a seat at the table when the government makes decisions about air travel.

Accelerating Kids’ Access to Care Act:

- This law provides access to health care for children with rare diseases.

Other legislative victories include:

- The Rare Pediatric Disease Priority Review Voucher Program, which encourages the development of treatments for rare pediatric diseases
- The Supplemental Social Security Income (SSI) Penalty Elimination Act, which would increase SSI asset limits
- The HCBS Access Act, which would increase access to in-home caregiving
- The HCBS Relief Act, which would provide temporary additional funding for HCBS services

As we look on to this new year, remember that a gift of any size can help transform lives through better care and more chances at a cure. NALC often reminds people: “You never know when it might be you.” God bless you all.