May 3rd, 2024

The Honorable Mike Johnson
568 Cannon House Office Building
Washington, D.C. 20515

The Honorable Hakeem Jeffries
2433 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

Re: The Neuromuscular Disease Community Supports Swift Enactment of the FAA Reauthorization Act of 2024

Dear Speaker Johnson, Minority Leader Jeffries, Majority Leader Schumer, and Minority Leader McConnell;

In service of the approximately 300,000 Americans living with a neuromuscular disease, for whom we collectively serve, the undersigned 31 patient advocacy organizations urge you to swiftly enact the FAA Reauthorization Act of 2024, which would represent the greatest progress in making air travel safer and more dignified for those with disabilities in nearly forty years.

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Most individuals with neuromuscular diseases experience progressive muscle weakening and loss due to their conditions which can often lead to a variety of disabilities, particularly mobility disabilities. Commercial air travel remains one of the most inaccessible and undignified experiences the neuromuscular disease community faces. Over 10,000 wheelchairs and scooters are mishandled every year, passengers are routinely injured and/or dropped in unsafe seat transfers, and airplanes are often entirely inaccessible to navigate. Furthermore, the laws and regulations governing the accessibility of air travel have changed little in the previous nearly forty years.

The accessibility provisions within the FAA Reauthorization Act of 2024 would make air travel substantially safer and more dignified for those with disabilities. The legislation would require the Department of Transportation (DOT) to complete all further research necessary to prepare policymakers to move forward with requiring wheelchair spots on airplanes. Robust and continuous training of baggage handlers stowing wheelchairs and scooters and personnel assisting with seat transfers would be required to substantially reduce the numbers of wheelchairs damaged and individuals injured. Evacuation standards would be studied and revised to consider those with disabilities, aircraft cargo hold dimensions must be publicized, on-board wheelchairs must be made available on flights with more than 60 seats, and a variety of additional provisions would together make air travel much safer and dignified for the neuromuscular disease community.

Consequently, we urge you to ensure the FAA Reauthorization Act of 2024 is swiftly enacted. The neuromuscular disease community has waited for an accessible air travel experience for long enough. If you have any questions or desire additional information, please do not hesitate to contact Shannon Wood, Director, Disability Policy at the Muscular Dystrophy Association at swood@mdausa.org or 202-836-2567.

Sincerely,

All Wheels Up
ALS Association
Charcot-Marie-Tooth Association (CMTA)
Charcot-Marie-Tooth Research Foundation (CMTRF)
Coalition to Cure Calpain 3
CureLGMD2i Foundation
Cure CMD
Cure VCP Disease
Cure Rare Disease
The Dion Foundation
A Foundation Building Strength for Nemaline Myopathy
Friedreich's Ataxia Research Alliance (FARA)
FSHD Society
Genetic ALS & FTD: End the Legacy
Hereditary Neuropathy Foundation
I AM ALS
Kennedys Disease Association
LGMD2i Research Fund
LGMD Awareness Foundation
Les Turner ALS Foundation
Little Hercules Foundation
Muscular Dystrophy Association
Myasthenia Gravis Foundation of America
Myositis Support and Understanding
Myotonic Dystrophy Foundation
National Ataxia Foundation
OPMD Association
Parent Project Muscular Dystrophy
The Speak Foundation
Team Titin
United Mitochondrial Disease Foundation

CC:

The Honorable Sam Graves, Chairman, House Committee on Transportation and Infrastructure
The Honorable Maria Cantwell, Chairwoman, Senate Committee on Commerce, Science, and Transportation
The Honorable Rick Larsen, Ranking Member, House Committee on Transportation and Infrastructure
The Honorable Ted Cruz, Ranking Member, Senate Committee on Commerce, Science, and Transportation