

May 3rd, 2024

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

The Honorable Chuck Schumer 322 Hart Senate Office Building Washington, D.C. 20510 The Honorable Hakeem Jeffries 2433 Rayburn House Office Building Washington, D.C. 20515

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.

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 <a href="mailto:swood@mdausa.org">swood@mdausa.org</a> 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, Panking Member, Senate Committee on Commerce, Science, and

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