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Written Testimony for the Record

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Accessible Air Travel: Addressing Challenges for Passengers with Disabilities

Chairman Larsen, Ranking Member Graves, and Members of the Subcommittee,

Thank you for holding a hearing to highlight the challenges air passengers with disabilities, including those with spinal muscular atrophy (SMA), face when traveling by air. As the leading national organization that advocates for children and adults with SMA, a neuromuscular disease that affects physical strength, Cure SMA is pleased to share the air travel perspective and experience of the SMA community and provide recommendations for Congress to consider in its reauthorization of the law governing the Federal Aviation Administration (FAA) and air travel in this country.

AIR TRAVEL CHALLENGES FOR WHEELCHAIR PASSENGERS WITH SMA

SMA is a progressive neurodegenerative disease that robs individuals of physical strength, often leading to loss of ambulation and fine motor skills. Many individuals with SMA use power wheelchairs that are tailored to their individualized SMA needs, such as extra back and side supports or a repositioning feature to improve function and breathing. *“Wheelchairs are our legs. Wheelchairs are a lifeline. Wheelchairs are independence,”* a **Florida woman with SMA** said about the importance of her wheelchair. A **Wisconsin man with SMA** said *“My power wheelchair is essential to my independence and well-being. It is not a piece of luggage; it is something that I rely on completely.”*

Based on the experience of air travelers with SMA, airlines do not seem to place the same value on wheelchairs in their handling and storage process. Many air travelers with SMA report air travel damage to their wheelchairs, despite their own pre-flight precautions. The preparations for a **California family with a child with SMA** start during the booking process to provide the airline with ample heads-up time. Once they arrange their flights, the family contacts the airline’s disability services representative about their son’s power wheelchair. They then arrive 3 or more hours early to the airport to begin their onsite steps. They reconfirm with the ticket agent and the gate attendant that the airline is prepared to stow their son’s powerchair. They then safeguard the wheelchair for storage in the cargo of the plane by bubble wrapping the chair, removing its joystick, and tagging the wheelchair with “do not tilt” and “push here” instructions. A **52-year-old adult with SMA** who travels regularly for work takes similar precautions. *“Given the essential nature of my wheelchair, I*

expect airlines and airport personnel to transport my wheelchair safely and securely 100% of the time. I estimate that I have experienced some type of damage to my wheelchair on 80% of my trips.” He went on to say damage ranges from “something minor, to complete destruction of the wheelchair.” Other wheelchair-related complaints reported to Cure SMA from individuals with SMA and their families included:

- *“My own specialized wheelchair (worth \$30,000) is broken almost every time I fly.”*
Maryland woman with SMA
- *“I am 33 years old, and in my life, I have had my wheelchair transferred to the wrong connecting flight and badly damaged in the luggage hold below the plane multiple times.”* **California man with SMA**
- *“People with SMA who travel by air must check their wheelchair with no confidence or assurance that their lifeline to independence and mobility will arrive undamaged.”*
Texas woman with SMA

In addition to problems associated with wheelchair stowage, air passengers with SMA also encounter common challenges related to seat transfers and inaccessible lavatories. Muscle atrophy and low body tone associated with SMA often prevents individuals with SMA from sitting independently in an aisle chair or aircraft seat without support. Many individuals with SMA are injured during the transfer process because aisle chairs offer limited support. A **woman with SMA** said *“It can be terrifying. I have been required to transfer out of my wheelchair under the supervision of strangers who have no knowledge about my physical capabilities, range of motion issues, and other critical aspects of my disability.”* Another **adult with SMA** pointed to limited seat and row space on an aircraft as contributing to unsafe seat transfers. *“My most difficult and most dangerous transfers have come from not having enough room between seats for someone to be on either side of me.”* Inaccessible lavatories also cause challenges for people with SMA. A recent Cure SMA survey found that air passengers with SMA dehydrate several hours before takeoff and schedule flights with multiple layovers rather than direct flights to allow for airport bathroom breaks.

IMPACT OF INACCESSIBLE AIR TRAVEL

Each month, the U.S. Department of Transportation (DOT) reports the number of customer complaints related to lost, mishandled, or damaged wheelchairs and scooters.ⁱ Behind each of these numbers is a story of consequence and loss, whether related to physical and emotional injury or lost opportunities and impacted meetings, vacations, and family events. A **New York man with SMA** said he declines work conferences and meetings due to inaccessible air travel. *“I would not have to be the ‘team member left home’ and could join my fellow teammates at these events if I could sit in my own chair for the duration of the flight rather than stow my wheelchair.”* A **woman with SMA** who travels a couple times a year for work factors time to repair a wheelchair damaged during travel into her plans. *“I usually travel in a day prior to the event to ensure I make it to the event in time and with a working chair. That way if the chair is damaged, I have a little time to try to get it fixed in advance of the actual event taking place the following day, assuming it’s nothing significant.”* A **California man with SMA** said *“I have lost days of travel, both vacation and work travel,*

trying to find a wheelchair repair shop in a new city, ordering parts, and scheduling maintenance.”

A **Texas mother of a teenager with SMA** described how several wheelchairs on her son’s wheelchair basketball team were significantly damaged while traveling for a basketball tournament. *“Not only was it a dangerous and humiliating situation, but the ramifications of a damaged custom mobility device can include missed school, missed work, and risk of health problems and/or injuries due to using an ill-suited loaner chair.”* Several individuals with SMA avoid air travel all together due to wheelchair damage concerns, despite the personal and professional cost to them. *“I have been unable to attend family weddings. I have missed out on school trips and study abroad opportunities,”* said a **Massachusetts man with SMA**.

SMA COMMUNITY RECOMMENDATIONS FOR FAA REAUTHORIZATION

Cure SMA applauds past actions by Congress to help make air travel more accessible for passengers with disabilities, first through the Air Carrier Access Act (P.L. 99-435) and then through subsequent FAA reauthorization bill improvements. The disability title in the 2018 FAA reauthorization bill (P.L. 115-254), for example, included several important provisions to help increase accessibility for passengers with disabilities, including the air passengers with disabilities bill of rights and the study on in-cabin wheelchair restraint systems.ⁱⁱ In addition, DOT continues its regulatory work related to accessible lavatories in single aisle aircraft and onboard wheelchair design. However, as **one adult with SMA** put it, *“accessible bathrooms and other incremental improvements are nice but the ability to stay in my own wheelchair during flights is far, far more important to me.”*

Cure SMA and the SMA community urges Congress to require that new aircraft design will accommodate the ability for a person with disability to roll onto the aircraft in their own wheelchair, use it as their airplane seat, and move within the cabin to access an accessible bathroom. Cure SMA supports provisions in the Air Carrier Access Amendments Act (H.R. 1696) to ensure that future aircraft “be designed to accommodate individuals with disabilities” through new design standards. *“I want to be able to roll my wheelchair onto the plane, lock in, and enjoy the flight like every other passenger,”* said an **adult with SMA**.

However, given the lengthy process to manufacture and operationalize new aircraft, the SMA community also urges Congress to take immediate steps to improve accessibility, including retrofitting existing aircraft to accommodate onboard wheelchair seating. The congressionally mandated study on wheelchair securement systems on aircraft (like those used in buses) found no formidable design and engineering challenges that would “call into question the technical feasibility of an in-cabin wheelchair securement system.”ⁱⁱⁱ Cure SMA supports efforts to fund and complete any final analysis, as recommended in the aircraft securement report, to address operational and passenger accommodation considerations for in-cabin wheelchair use on existing aircraft. Other short-term improvements could include additional staff training related to wheelchair stowage and handling and new aisle chairs that included seat elevators to promote safe transfers.

CONCLUSION

Air travel in the U.S. for individuals with SMA and other disabilities should be accessible and equal. It should not be a “*roll of the dice*” situation as **one person with SMA** described. Congressional inaction on this important issue will only increase transportation barriers faced by air travelers with SMA and other disabilities, which represents a large segment of the U.S. population. According to a recent national study organized by Paralyzed Veterans of America, Cure SMA, and other national disability organizations, more than 75 percent of people with disabilities would fly at least a few times a year if the current air travel problems for passengers with disabilities were addressed.^{iv} As you consider improvements for air travel for passengers with disabilities, Cure SMA encourages you to examine proposals through the lens of a power wheelchair user with SMA. *“I would love nothing more than to travel around the world and experience travel the same way as able-bodied people. However, due to the complicated, unsafe nature of traveling as a disabled person currently, flying has become an anxiety-inducing nightmare.”*

Thank you for considering the views of Cure SMA and the SMA community.

ⁱ Air Travel Consumer Report, U.S. Department of Transportation, 2022, <https://www.transportation.gov/individuals/aviation-consumer-protection/air-travel-consumer-reports>

ⁱⁱ FAA Reauthorization Act of 2018, P.L. 115-254, 2018, <https://www.congress.gov/115/plaws/publ254/PLAW-115publ254.pdf>

ⁱⁱⁱ Study on the Feasibility of Wheelchair Restraint Systems in Passenger Aircraft, National Academies of Sciences, 2021,

<https://www.nationalacademies.org/our-work/committee-for-a-study-on-the-feasibility-of-wheelchair-restraint-systems-in-passenger-aircraft>
^{iv} ACAA Survey, Paralyzed Veterans of America, Cure SMA, and National Disability Organizations, 2022 <https://pva.org/wp-content/uploads/2022/09/2022-ACAA-Survey-Results-FINAL.pdf>