



Make today a breakthrough.

August 30, 2021

Air Carrier Access Act Advisory Committee
c/o U.S. Department of Transportation
Office of the Secretary
1200 New Jersey Ave SE
Washington, DC 20590

Dear Members of the Air Carrier Access Act (ACAA) Advisory Committee:

As the leading national organization that supports and advocates for individuals with spinal muscular atrophy (SMA), **Cure SMA is pleased to share our perspective on air travel challenges faced by individuals with SMA (especially those who utilize power wheelchairs) and to provide feedback on the Subcommittee findings and recommendations for stowage of assistive devices and airport and aircraft assistance.**

SMA is a degenerative disease that robs individuals of physical strength, greatly impacting their ability to walk, eat, and perform other essential functions of everyday life. Individuals with SMA who utilize power wheelchairs for their mobility face regular challenges when traveling by air, especially related to wheelchair stowage and passenger transport.

A **California family with a child with SMA** have encountered numerous problems throughout the air travel process, from booking to deplaning, but none as consequential as wheelchair storage. At the airport, before checking their son's 400 pounds and 4½ feet tall power wheelchair, the family removes potentially breakable parts, such as the joystick, and then covers the chair with several layers of plastic cellophane wrap for extra protection. Using plastic zip ties, they attach laminated English and Spanish language instructions (with pictures) for proper storage and use, including how to move the chair and lock and unlock the brakes. Even with all these precautions, they often end up with a damaged chair in the end. "It's difficult watching them from the plane window as they mishandle the chair, such as flipping it on its side and mashing it trying to get it through the small cargo hole."

Cure SMA and the individuals with SMA across the country we represent appreciate the work of the ACAA Advisory Committee and Subcommittees to identify barriers and make recommendations for improving accessible air travel.

SUBCOMMITTEE ON STOWAGE OF ASSISTIVE DEVICES RECOMMENDATIONS

We are especially focused on the work of the Subcommittee on Stowage of Assistive Devices given damage to power wheelchairs was a top concern identified by adults with SMA. A **46-year-old Illinois man with SMA Type 3** described how the inconsistent handling of wheelchairs to the cargo hold and inability to provide communication directly to those

responsible for stowage adds to the stress of an already stressful travel experience. A **27-year-old Florida woman with SMA Type 2** referenced how past damage to her wheelchair has limited her opportunities to fly. “It’s terrifying to have your only source of independence in jeopardy. Wheelchairs are our legs. Wheelchairs are a lifeline. Wheelchairs are independence.”

The Subcommittee on Stowage of Assistive Devices described in its [2021 report](#) how damage to wheelchairs or scooters was a serious concern for most passengers with disabilities traveling by air with these devices. The Subcommittee focused on the causes of damaged and mishandled mobility and assistive devices. The Subcommittee’s findings related to small cargo door openings and a lack of wheelchair testing and securement standards for air transport are important considerations. **Cure SMA supports the recommendations related to establishing consistent labeling and securement standards and studying design improvements and innovations for storing power wheelchairs in the cargo compartment of narrow- and wide-bodied aircraft.**

The Subcommittee also reviewed the training of airline employees and contractors who handle assistive devices, such as power wheelchairs, and found that most airlines provide initial in-person training and ongoing online training for cabin and cargo stowage, battery identification and handling, and passenger interactions. The Subcommittee did not recommend regulatory or other changes related to airline training following its review of existing employee training. Air travel for wheelchair users, no matter where the destination, remains a complicated and unpredictable experience filled with disappointment and heartache. **Cure SMA believes more effective training is needed to improve the air travel experience for power wheelchair users, given the limited knowledge of and confusion around chair storage and handling.**

A **24-year-old Virginia woman with SMA Type 3** described how she says “a little prayer” while stowage staff take her chair away to be loaded underneath the belly of the plane, even after taking numerous precautions, such as bubble-wrapping her chair and attaching picture instructions such as *push here* and *don’t turn on its side*. “It is very scary to look out the window and watching them turn your chair completely on its side and put it up a conveyor belt.” The Subcommittee report noted that tipping a power wheelchair on its side or forcing it through the cargo door “can result in damage to the device or to the aircraft.” Additional training—along with the Subcommittee’s other recommendations (i.e., standard Wheelchair and Scooter Handling Checklists)—would better prepare stowage and airport staff, prevent power wheelchair damage, and improve the travel experience. Based on past damage to her checked power wheelchair, **a 34-year-old woman with SMA Type 3** who works full-time schedules a flight an entire day prior to her work event to mitigate problems. “That way if the chair is damaged, I have more time to get it fixed in advance of the actual event taking place the following day, assuming the damage is not significant.” Another **person with SMA** described needing to travel with a toolkit with extra parts in case her chair was damaged. **Cure SMA asks that the ACAA Advisory Committee reconsider its non-recommendation related to training of airline operations staff.**

SUBCOMMITTEE ON AIRPORT AND AIRCRAFT ASSISTANCE RECOMMENDATIONS

Cure SMA also appreciates the work of the Subcommittee on Assistance at Airports and on Aircraft and Related Training, especially related to the use of aisle chairs and the passenger aircraft experience. The Subcommittee found in its [2021 report](#) that inadequate wheelchair assistance was the top disability complaint category received by airlines. **Individuals with SMA also ranked aircraft transfer and travel experience as top concerns.**

Because power wheelchair cannot be used on aircraft, passengers with SMA and other non-ambulatory individuals depend on staff assistance and aisle chairs (also referred to as boarding chairs) to board onto commercial aircraft. Due to muscle atrophy and low body tone associated with SMA, many individuals with SMA are unable to sit independently in an aisle chair or aircraft seat without support. Because of limited support in the current aisle chair design, many individuals with SMA are injured during the transfer and boarding process. An **adult with SMA** reported spending her “entire trip in excruciating pain” after being injured during an aisle chair transfer. A **65-year-old with SMA** has avoided air travel for several years due to the difficulty in boarding. “The last time I suffered severe back pain and was extremely uncomfortable in the seats due to my spinal scoliosis.” **Cure SMA supports the Subcommittee’s recommendation to study aisle chair design and the use of lift devices to improve the aisle transfer process for passengers who utilize wheelchairs.**

The air travel experience for individuals with SMA and other significant disabilities remains vastly different and unequal than for passengers without disabilities. Cure SMA supported the FAA Reauthorization Act of 2018 provision to study the feasibility of wheelchair restraint systems in passenger aircraft. **Cure SMA was pleased that the Subcommittee voted unanimously to recognize and support the U.S. Access Board study, including a recommendation that the study be “completed in a prompt manner.”** Until a passenger with SMA can roll onto the aircraft and use their own wheelchair as their aircraft seat, the air experience will continue to be different, unsafe, and—often—undignified. “Using my personal wheelchair with a seating system that accommodates me would make a world of difference,” a **person with SMA** said.

AIRLINE PASSENGERS WITH DISABILITIES BILL OF RIGHTS

Finally, Cure SMA urges the ACAA Advisory Committee and the U.S. Department of Transportation to adopt the draft [Airline Passengers with Disabilities Bill of Rights](#). As required under Section 434 of the FAA Reauthorization Act of 2018, the Airline Passengers with Disabilities Bill of Rights simply highlights existing protections for air travelers with disabilities and responsibilities of airlines and their employees and contractors. Adoption of the Airline Passengers with Disabilities Bill of Rights would elevate awareness of and understanding of these basic rights and responsibilities, which could lead to improved travel experiences for air travelers with SMA and other disabilities. The sections of most interest and relevance to the SMA community are related to passenger assistance, accessible aircraft, traveling with assistive devices, such as power wheelchairs, and the use of ramps and mechanical lifts when



level-entry boarding is not available. In Section 7, related to checking and returning assistive devices, **Cure SMA recommends that the bill of rights draft more clearly state that mobility and assistive devices, such as power wheelchairs, should be returned undamaged by using language from the Subcommittee on Stowage of Assistive Devices report: “Wheelchairs, other mobility aid devices, and assistive devices must be returned to passengers in the same condition in which they were received.”**

Cure SMA is encouraged by the work and dedication of the ACAA Advisory Committee and urges the Committee and all policymakers to continue to improve the air travel experience for people with disabilities, including passengers with SMA. Thank you for considering our views. For more information, your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004.

Sincerely,

A handwritten signature in black ink that reads "K. A. Hobby".

Kenneth Hobby
President
Cure SMA

A handwritten signature in black ink that reads "Maynard Friesz".

Maynard Friesz
Vice President of Policy & Advocacy
Cure SMA