



Make today a breakthrough.

March 17, 2022

The Honorable Pete Buttigieg  
Secretary  
U.S. Department of Transportation  
1200 New Jersey Avenue, SE  
Washington, D.C. 20590

Dear Secretary Buttigieg:

As the leading national organization that supports and advocates for individuals with a rare disease known as spinal muscular atrophy (SMA), **Cure SMA thanks the U.S. Department of Transportation (DOT) for hosting a public meeting to learn about the barriers and difficulties individuals with SMA and other air travelers who use a wheelchair face when they travel by air.** We appreciate the opportunity to share the experiences of children and adults with SMA and their families.

SMA is a degenerative neuromuscular disease that robs individuals of physical strength, greatly impacting their ability to walk, eat independently, 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 aisle chair transfer, two of the areas DOT seeks information on *“to determine what appropriate steps can be taken to improve accessibility for wheelchair users.”*<sup>i</sup>

**Cure SMA appreciates DOT’s stated commitment to *“improving the accessibility of air transportation for people with disabilities.”***<sup>ii</sup> The SMA community has closely followed DOT’s recent work related to the Air Carrier Access Act (ACAA) Advisory Committee, accessible lavatories regulations, airline passengers with disabilities bill of rights, and related air travel activities. These meaningful efforts will help to improve the air travel experience for people with SMA and other disabilities. However, until a passenger with SMA can roll onto a commercial aircraft and use their own wheelchair as their aircraft seat, the air experience will not truly be equal or accessible compared to air travelers without disabilities. That is why Cure SMA is working with other national organizations toward the goal of making in-cabin wheelchair travel a reality, especially given the recent congressionally mandated study that found an in-cabin wheelchair securement system was technically feasible.<sup>iii</sup> A **25-year-old traveler with SMA** succinctly described the community’s goal in her statement: *“like a train or bus, I want to be able to roll onto the plane, on my wheelchair, and never have to transfer.”*

**In the meantime, the SMA community is grateful for the opportunity to inform DOT as it considers next steps for improving the air travel experience for wheelchair users with SMA and other disabilities.** Cure SMA’s comments, which reflect the experiences of adults with SMA and families of children with SMA, will focus on three categories posed in the meeting

notice: challenges encountered during air travel, impacts of mishandled wheelchairs, and experiences related to transfers to and from the aircraft seat.

## QUESTIONS RELATING TO CHALLENGES ENCOUNTERED DURING AIR TRAVEL BY PERSONS WHO USE A WHEELCHAIR AND THE IMPACTS ON UNSAFE OR INADEQUATE ASSISTANCE

Unequal, unsafe, and unsatisfactory are words that many individuals with SMA who utilize a motorized wheelchair use to describe their air travel experiences. The cumulative effect of wheelchair damage, inaccessible bathrooms, and aisle chair transfer injuries is that wheelchair users with SMA often limit or avoid air travel, which greatly impacts their ability to earn a living, see their family, and explore the world.

A **66-year-old Arizona resident with SMA** regularly traveled for work. *“Eventually, I had to give up air travel do to successive and numerous personal injuries that occurred during transfers to and from aisle chairs, and 4 successive flights that rendered my custom power chair unusable and a 5th where the chair had to be repaired after a TSA search.”* A **Louisiana working professional with SMA**, who has experienced damaged equipment on past plane trips, has concluded that air travel risks outweigh the benefits. *“I have been unable to attend employer-sponsored trainings and promotions with travel requirements due to inaccessible air travel. I would love to travel but cannot confidently do so until changes take place.”* A **New York resident with SMA** who works in the software industry also described having to decline invitations to work conferences due to air travel challenges. *“If air travel could be made more accessible, where I did not have to stow my wheelchair and could sit in it for the duration of a flight, I would not have to be ‘the team member left home’ and could join my fellow teammates at the events.”* A **young business professional with SMA** worries about the impact inaccessible air travel will have on her work career. *“What if I can’t get to a work meeting on time because my chair is damaged. This is possible. It’s one extra thing that I must think about that not anyone else on the plane has to think about.”* An **Illinois woman with SMA** who travels a couple times a year for work isolates her pre-trip schedule to factor in potential wheelchair damage. *“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.”*

Inaccessible air travel for individuals who use wheelchairs also includes personal and family costs. *“I have been unable to attend family weddings. I have missed out on school trips and study abroad opportunities. I have had fewer and shorter chances to explore this beautiful country,”* recounted a **Massachusetts man with SMA**. A **Texas mother with a child with SMA** is unable to satisfy her daughter’s curiosity about the world. *“I always imagined raising my children to be travelers, but her use of a power wheelchair has prevented us from flying with the real concern that her chair - her mode of independence, her legs! - would not survive the trip without damage. The lack of accessible air travel is a big limitation for her life and something that can and should be changed.”*

**The difficulties identified by people with SMA match the experiences of the wider disability community**, according to a 2021 survey conducted during the 35th anniversary of the ACAA and sponsored by national organizations, including Cure SMA and Paralyzed Veterans of America. Of the more than 1,260 people with disabilities, including SMA, who responded to the ACAA survey (between October 4 and December 6, 2021), nearly all respondents (1,180) said that they would travel by air, at least once a year, if their concerns about aisle chair transfer, damaged wheelchair, and other challenges were addressed. About 60 percent (700) of survey respondents said they would fly a few times a year, highlighting the utilization and financial cost the airline industry experiences because of the current air travel barriers for wheelchair users with disabilities.

### QUESTIONS RELATING TO ACTIONS TO PREVENT OR MINIMIZE LIKELIHOOD OF MISHANDLED (DAMAGED, DELAYED, AND LOST) WHEELCHAIRS

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. A **Cure SMA family from California** described the numerous precautions they take to protect the powerchair of their son with SMA—from bubble-wrapping the chair and disassembling breakable parts (i.e., joystick) to tagging the chair with visual instructions for moving and lifting, including a personal plea to *take good care* of the equipment. A **Virginia woman with SMA** takes similar precautions, including taping multiple instruction signs to her power wheelchair, including *pull here, push here, and weighs 300 pounds, don't carry up a flight of stairs*. Even with the preparation and instructions, inevitably, the fate of her wheelchair is out of her hands. *"You just have to say a prayer while they take the chair down to be loaded underneath in the belly of the plane."*

DOT highlighted the wheelchair problem in its meeting announcement by noting that the largest U.S. airlines have *"collectively mishandled more than one in every one-hundred wheelchairs they transported."* Individuals with SMA who use wheelchairs are included in that statistic, which is very likely underreported across all airlines. Wheelchair-related complaints reported to Cure SMA from *individuals with SMA and their families* include:

- *"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**
- *"The majority of trips I experienced damage to my wheelchair, ranging from minor to extensive requiring significant repairs and time without my primary mobility device."*  
**Wisconsin man with SMA**
- *"Every time my daughter flies, something is broken on her wheelchair because the airline employees are not careful loading and securing her wheelchair."* **California father with a child with SMA**

A single air travel experience that results in damage to the person's lifeline to mobility and independence will forever impact that traveler. *"It's a terrifying feeling to have your only source of independence in jeopardy"* a **Florida woman with SMA** wrote about wheelchair damage impact. *"Wheelchairs are our legs. Wheelchairs are a lifeline. Wheelchairs are independence."* A **Virginia man with SMA** concurred. *"As my disease has progressed, my wheelchair has become more and more specialized, fragile, and expensive. I have not flown on a commercial flight in more than two decades due to past experiences of my wheelchair being damaged by airlines."*

## QUESTIONS RELATING TO ACTIONS TO ENSURE SAFE TRANSFERS TO AND FROM THE AIRCRAFT SEAT

The transfer to and from aircraft seats is a top concern for individuals with SMA who use wheelchairs. 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 current aisle chairs offer limited support, many individuals with SMA are injured during the transfer process.

A **Texas woman with SMA** who describes herself as *"completely non-ambulatory,"* but *"loves the experience of flying and seeing new places,"* has experienced unsafe transfers. *"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."* A **Georgia man with SMA** described the transfer as *"painful and unsafe"* while another **adult with SMA** reported spending her *"entire trip in excruciating pain"* due to an injury incurred during an aisle chair transfer. A **woman with SMA** who travels for work said, *"transferring onto the plane and sitting in a regular seat with no support is really hard on my body. I have to bring multiple travel pillows to put around me for support and a blow up one to prop my feet up as well, so they aren't hanging the entire flight."*

Many individuals and families do not travel by air due to the unsafe chair transfer. A **California mother said her daughter with SMA** is unable to sit in an aisle chair *"without a custom seating system that includes a full harness. We stopped traveling by plane because of it."* The family forgoes air travel completely due to this problem, a common theme, where more than 54 percent of ACAA survey respondents said the airline transfer was one of the top concerns for avoiding air travel.

## CLOSING COMMENTS

Cure SMA and the SMA community recognize that progress has been made since the 1986 ACAA law in addressing air travel challenges faced by people with disabilities, including the disability provisions included in the last Federal Aviation Administration reauthorization bill.<sup>iv</sup> However, more can and must be done to bring air travel in line with other modes of transportation. *"Flying does not feel like a means of transportation as much as it feels like a*



*horrible and unfair gamble,*" one **person with SMA** aptly described. We hope that Cure SMA's comments will be helpful in informing DOT about the challenges that remain so that air travel becomes a more viable means of transportation for people with SMA and others who use wheelchairs.

Thank you for the opportunity to provide comment on the air travel challenges of people with SMA. For more information, please contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at [maynard.friesz@curesma.org](mailto:maynard.friesz@curesma.org) or 202-871-8004.

Sincerely,

A handwritten signature in black ink that reads "K. 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

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<sup>i</sup> Federal Register, March 15, 2022, <https://www.govinfo.gov/content/pkg/FR-2022-03-15/pdf/2022-05422.pdf>

<sup>ii</sup> Notice of Public Meeting, U.S. Department of Transportation, 2022, <https://www.transportation.gov/individuals/aviation-consumer-protection/air-travel-persons-who-use-wheelchairs-notice-public>

<sup>iii</sup> National Academy of Sciences Wheelchair Security Feasibility Study, 2021, <https://www.nationalacademies.org/our-work/committee-for-a-study-on-the-feasibility-of-wheelchair-restraint-systems-in-passenger-aircraft>

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