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Written Testimony for the Record

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**U.S. Senate Commerce Committee
March 23, 2023 Hearing on**

Enhancing Consumer Protections and Connectivity in Air Transportation

Chair Cantwell, Ranking Member Cruz, and Members of the Committee,

Thank you for holding a hearing focused on strengthening consumer protections for the U.S. flying public, including individuals with spinal muscular atrophy (SMA) and other disabilities. 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 experiences and recommendations of the SMA community to help inform this distinguished Committee as it crafts the next Federal Aviation Administration (FAA) reauthorization bill.

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. *“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,”* said a **Wisconsin man with SMA**.

Individuals with SMA and their families often travel long distances to attend work meetings, participate in clinical trials, or connect with family and friends. While air travel may represent the most obvious travel option due to distance, many adults with SMA and families with children with SMA avoid or only reluctantly travel by airplane due to uncertain, unsafe, and unsatisfactory past experiences. *“Flying does not feel like a means of transportation as much as it feels like a horrible and unfair gamble,”* said a **Texas woman with SMA**.

Cure SMA released a nationwide report in February to outline the air travel experiences of people with SMA from across the country.¹ Individuals with SMA and their families pointed to skilled and considerate staff and crew for when their air travel went smoothly. A **24-year-old adult with SMA from Illinois** shared his positive experience in the 2023 report: *“The first time I flew on an airplane with my wheelchair, the flight crew was very kind and understanding. They made sure my needs were met and that my wheelchair was not damaged. They took extra caution to ensure I would have a good experience, and it certainly worked out.”*

However, most air travel experiences shared by the SMA community were “bad” and “ugly.” Lost and damaged wheelchairs were primary causes of bad air travel experiences. *“I’ve seen my chair fall down a flight of stairs on the tarmac,”* said a **Minnesota woman with SMA**. A **Texas woman with SMA** had a similar experience. *“My chair was dropped as it came off the luggage belt out of the plane and the wheel broke, the armrest flew off, and the joystick was damaged.”* An **Arizona woman with SMA** added: *“Those of us who use a power wheelchair and like to travel, by air, do so without confidence or reassurance that our ‘legs’ used for daily independence and mobility will arrive undamaged.”*

Several SMA community members also reported air travel injuries, usually during the transfers in and out of the aircraft seats. A **Tennessee woman with SMA** described an incident where the passenger transport attendants *“were jamming the armrest into my back. It was so bad the fellow flyers were apologizing and asking if I was ok. I ended up with a huge bruise on my back.”* A **Florida man with SMA** shared that during one aisle chair transfer, staff *“almost broke my arm trying to lift me. While they didn’t break it, they did injure me by pulling a muscle in my shoulder.”* An **Oklahoma woman with SMA** reported pressure sores and other health problems following one trip that included a long delay. Beyond wheelchair damage and personal injuries, the SMA community also pointed to inaccessible lavatories, space constraints, and limited boarding time as contributing to stressful, humiliating, and dehumanizing air travel. *“When the pilot says, ‘sit back, relax, and enjoy the flight’, that ought to refer to everyone!”* a **mother of a child with SMA** summarized.

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.ⁱⁱ 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 **California man with SMA** shared: *“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.”* An **Illinois 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 **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 in 2022. *“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. 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 **Massachusetts man with SMA** said “I have been unable to attend family weddings. I have missed out on school trips and study abroad opportunities.”*

SMA COMMUNITY RECOMMENDATIONS FOR FAA REAUTHORIZATION

Cure SMA applauds past actions by Congress to 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.ⁱⁱⁱ In addition, DOT continues its regulatory work related to accessible lavatories in single aisle aircraft, onboard wheelchair design, and a forthcoming proposal related to safe accommodations for air passengers with disabilities who travel in wheelchairs.^{iv}

Cure SMA identified the SMA community priorities for the 2023 FAA reauthorization bill in its air travel report. Short-term recommendations included enhanced boarding procedures, improved cargo securement for wheelchairs, increased seat dimensions, disability training for staff, and required equipment. However, as a **Virginia man 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.*” The SMA community also asks Congress to take meaningful steps this year toward allowing individuals with disabilities to use their own wheelchair as their aircraft seat. “*Being able to fly with our daughter’s wheelchair would allow our family to go on vacations out of state, visit with out of state family members (that she hasn’t seen in years), and allow her to participate in out of state clinical trials,*” said a **California parent of a child with SMA**.

Cure SMA is supportive of legislation that would help achieve the short- and long-term goals of the SMA community. Cure SMA urges the Commerce Committee to include provisions from the following legislation in the next FAA reauthorization:

- [Air Carrier Access Amendments Act \(S. 545\)](#): Legislation sponsored by Senator Tammy Baldwin and supported by other Commerce Committee Members to, among other things, set new accessible standards for aircraft and strengthen the complaints process for passengers with disabilities who experience a damaged wheelchair.
- [Prioritizing Accountability and Accessibility for Aviation Consumers Act \(S. 400\)](#): legislation sponsored by Senator Tammy Duckworth and Senator Deb Fischer to require DOT to report on aviation consumer complaints related to passengers with a disability.

In addition, we support proposals being developed to increase accessibility at airports and to empower passengers who use power wheelchairs and other mobility devices, including

requiring DOT to develop research and analysis toward the goal of accommodating passengers with wheelchairs in the main cabin during flight.

CONCLUSION

Air travel in this country should be more accessible and responsive to the needs of passengers with SMA and other disabilities. The SMA community appreciates the Commerce Committee's focus on improving the air travel experience for the U.S. flying public. Cure SMA respectfully asks that you include a disability title in the 2023 FAA reauthorization bill with provisions that can "*unlock the world for all folks with disabilities to travel,*" as an **adult with SMA** put it about the possibility of traveling safely and freely in his wheelchair. Thank you for the opportunity to provide the views and perspective of the SMA community.

ⁱ The Good, but mostly Bad and Ugly of Air Travel for Individuals with Spinal Muscular Atrophy, Cure SMA, February, 2023, <https://www.curesma.org/wp-content/uploads/2023/02/Cure-SMA-Good-but-mostly-Bad-and-Ugly-of-Air-Travel-for-People-with-Spinal-Muscular-Atrophy-1.pdf>

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

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

^{iv} Ensuring Safe Accommodations for Air Travelers with Disabilities Using Wheelchairs Proposed Rule, U.S. Department of Transportation, 2023 Unified Federal Regulatory Agenda, <https://www.reginfo.gov/public/do/eAgendaViewRule?pubId=202210&RIN=2105-AF14>