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May 12, 2022

Ms. Blane Workie
Assistant General Counsel
Office of Aviation Consumer Protection
U.S. Department of Transportation
1200 New Jersey Avenue, SE
Washington, DC 20590

Re: Comments related to the Accessible Lavatories on Single-Aisle Aircraft Part 2 NPRN

Dear Ms. Workie:

As the leading national organization that supports and advocates for individuals with a rare disease known as spinal muscular atrophy (SMA), **Cure SMA is pleased to share feedback from the SMA community on the U.S. Department of Transportation's (DOT) proposed rule related to accessible lavatories on single-aisle aircraft (Part 2).**ⁱ While requiring an accessible lavatory on new single-aisle aircraft represents a long overdue step forward, the SMA community stands united in supporting broader efforts to make it possible for a person with SMA and others to use their own power wheelchair as their in-cabin passenger seat.

SMA is a degenerative neuromuscular disease that robs individuals of physical strength, greatly impacting their ability to walk, sit without supports, and perform other essential functions of everyday life. Muscle weakness can manifest throughout the body and can progress over time, often leading to loss of ambulation and loss of fine motor skills. Many individuals with SMA use power wheelchairs that are tailored to their individualized SMA needs. For example, a power wheelchair for a person with SMA may include a customized seating system with extra back and side supports or a repositioning and positioning feature to improve function and breathing. *"Wheelchairs are our legs. Wheelchairs are a lifeline. Wheelchairs are independence,"* a **Florida woman with SMA** wrote in describing the importance of her wheelchair in her everyday life.

As Cure SMA described in written comments for DOT's March 24, 2022 Meeting on Air Travel by Persons Who Use Wheelchairs,ⁱⁱ adults with SMA and families of children with SMA face significant barriers when they travel by air for work, recreation, or to participate in a clinical trial. Cure SMA appreciates DOT's efforts to help address one of the barriers to air travel for individuals with SMA: inaccessible bathrooms. About 79% of adults with SMA and families of children with SMA who responded to a 2022 informal Cure SMA survey said the inability to use the airplane bathroom was a top reason for avoiding air travel. However, when air travel is the only option (i.e., due to distance), individuals with SMA said they take several precautions before boarding an airplane, including dehydrating several hours before the flight departs (62% of all respondents), using the bathroom right before boarding (57%), and choosing shorter flights with layovers (41%).

While efforts to improve lavatory accessibility are appreciated, **the top air travel priority of individuals with SMA and their families remains the ability to use personal wheelchairs directly on an airplane.** While not the focus of Cure SMA's survey nor this notice of proposed rulemaking (NPRM), several survey respondents reiterated their goal of rolling onto a commercial aircraft and using their own wheelchair as their aircraft seat. *"Bathrooms are not as important as staying in the chair while flying would be though! That would be the number one thing to make me travel more,"* said an **Oklahoma woman with SMA.** A **Virginia man with SMA** shared a similar view. *"To be honest, accessible bathrooms 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 that we represent welcome the opportunity to work with DOT and other stakeholders to make in-cabin wheelchair use a reality for individuals with SMA. In the meantime, we are pleased to provide the following feedback related to questions and themes raised in the NPRM on accessible lavatories on single-aisle aircraft (Part 2).

CURE SMA RESPONSE TO THE FOLLOWING NPRM QUESTIONS:

- **To what extent do accessible lavatories on twin-aisle aircraft meet the needs of passengers with disabilities, particularly passengers with mobility impairments?**
- **Are accessible lavatories on twin-aisle aircraft large enough to accommodate an assistant to assist the passenger with transfers between the OBW and the toilet?**

The views and experiences of individuals with SMA and their families who responded to Cure SMA's accessible lavatory survey were mixed on the use of twin-aisle accessible lavatories. Only 20% of survey respondents said they had ever used an accessible lavatory on a twin-aisle airplane. *"I have never seen an accessible bathroom on an aircraft. Especially one that would accommodate a wheelchair user,"* said an **Alabama mother of a child with SMA.** This common sentiment is likely because most U.S. domestic flights occur on single-aisle aircraft that do not have accessible bathrooms.ⁱⁱⁱ Only 9% of Cure SMA survey respondents who reported using twin-aisle accessible lavatories described the experience as being positive. *"We used one on a Lufthansa flight from Germany. It worked fine for us,"* said a **Massachusetts mother of a child with SMA.** A **young adult with SMA from Arizona** said the accessible bathroom met her needs. *"But I am a very small person,"* she added.

Most survey respondents with SMA reported challenges because the bathroom was not large enough to accommodate another person or to enter with an onboard wheelchair (OBW) and then transfer to the toilet. A **California father with a child with SMA** said it was *"impossible to get a wheelchair in the bathroom and close the door."* An **Oregon teenager with SMA** who has used an accessible lavatory on a twin-aisle plane said, *"it was almost impossible to fit two people in without getting hurt. I got hit on the walls multiple times."*

Because of space concerns with existing accessible bathrooms, Cure SMA does not support DOT's "alternative" proposal to allow for a smaller lavatory footprint. Every person who responded to Cure SMA's accessible lavatory survey said they needed at least one

other person to assist inside the bathroom. *"I would not be able to move around to get clothing up or down without the assistance of a second person,"* said a **Tennessee woman with SMA**. *"I have advanced SMA and need the assistance of a family member or personal assistant to help me,"* said a **California woman with SMA**. An **Arizona woman with SMA** said, *"I do need assistance from a family member because I am not able to transfer and undress/dress myself after using the bathroom."* Cure SMA and the SMA community urges DOT to increase – not decrease – the footprint of an accessible lavatory on single- and twin-aisle aircraft to make them more accessible for passengers with disabilities. Air travelers with SMA already face uncertainty and barriers related to existing accessible lavatories. *"I haven't used them because I didn't think the bathroom would be big enough for me and my caregiver to fit in and be able to do a transfers,"* a **woman with SMA from Michigan** said about the existing twin-aisle aircraft. Promulgating an accessible lavatory rule to allow accessible lavatories to decrease in size would not reduce barriers or promote greater access for passengers with disabilities, as intended in this NPRM.

CURE SMA RESPONSE TO THE FOLLOWING NPRM QUESTION:

- **If a carrier does have aircraft in its fleet with accessible lavatories, how would passengers with disabilities know or ensure that their specific flight is being operated using an aircraft equipped with an accessible lavatory?**

Cure SMA agrees that passenger education is needed when a flight is equipped with an accessible lavatory and onboard wheelchair. Many individuals with SMA who responded to Cure SMA's survey on accessible aircraft lavatories, including those who have flown on twin-aisle aircraft, were unaware or unsure about the accessible lavatory and equipment on the airplane. *"I have never seen an accessible lavatory on an airplane"* said a **woman with SMA from Puerto Rico**. Others noted that they were unaware that OBWs existed. The **Oregon teenager with SMA** who described her experience with twin-aisle accessible lavatories did not use an OBW to the lavatory. *"I did not know that OBW was an option, my parents always have to carry me."* A similar view was shared by a **Texas man with SMA** who said, *"I didn't know OBWs existed until this survey. Regardless, an OBW wouldn't help as I have to be lifted into it and that wouldn't be safe mid-flight."* Cure SMA believes that it is the responsibility of DOT and the airlines to ensure that passengers with disabilities are informed when an aircraft contains an accessible lavatory and onboard wheelchair. This education should include specific information about the lavatory size to ensure that passengers with disabilities who need assistance know in advance whether the lavatory will work for them to avoid what an **Indiana woman with SMA** faced on one of her international flights. *"The flight attendant had to hold up a towel over the door because the door didn't shut with my assistant and I both in there."*

CURE SMA GENERAL COMMENTS ON ONBOARD WHEELCHAIRS

Cure SMA is aware that DOT intends to gather additional information, including through a future public meeting, about OBW design and use. However, in response to the Cure SMA survey on accessible lavatories, many respondents volunteered challenges with current OBWs. Due to muscle atrophy associated with SMA, many individuals with SMA are not able to sit



independently without supports that are tailored to their condition and body. A **New York man with SMA** said, *“I have not used an OBW. However, I can tell you that they would not work for me as I require a custom seating system to sit safely upright.”* A **Massachusetts man with SMA** said OBWs *“lack lateral support that I need to sit upright.”* A **woman with SMA from Texas** said, *“I’m a Type 1 SMA, so I can’t hold my head on the OBWs.”* A **California woman with SMA** described similar limitations with OBWs. *“They do not offer the specific support that my body type needs.”*

Even for individuals with SMA who require limited or no specialized head and body support, the OBW should be improved. A **New Jersey woman with SMA** described her OBW experience as *“bumpy and overall uncomfortable. Makes me feel very out of control.”* A **Pennsylvania woman with SMA** was the lone survey respondent who gave the current OBW satisfactory marks. *“I’m lucky enough that the onboard transfer wheelchairs aren’t a major problem for me,”* she said.

CURE SMA FINAL COMMENTS

While we are supportive of improvements to accessible lavatories on single- and twin-aisle aircraft, many individuals with SMA would still be unable to use the bathrooms without also being able to use their specialized wheelchairs onboard the plane. A **Colorado mother of a child with SMA** said, *“my son requires the support of his personal wheelchair and the space for his medical equipment that is built into his chair. He cannot sit upright unassisted and is unable to fly due to the requirement to get out of his chair.”* A **Rhode Island mother of a child with SMA** summed up the SMA community’s accessible air travel goal when she wrote, *“it would be SO nice to have access to an onboard accessible bathroom. And if he could stay in his power chair on the plane, that would be even better.”* For some children and adults with SMA, the addition of an accessible lavatory without also allowing them to use their specialized wheelchair on the airplane would not represent accessibility or a workable solution.

Thank you for the opportunity to provide comment on the air travel challenges of people with SMA, including their views and experience with onboard lavatories. For more information, please contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004.

Sincerely,

Kenneth Hobby
President
Cure SMA

Maynard Friesz
Vice President of Policy & Advocacy
Cure SMA



ⁱ Federal Register, March 29, 2022, <https://www.govinfo.gov/content/pkg/FR-2022-03-28/pdf/2022-05869.pdf>

ⁱⁱ Cure SMA Public Comments for Public Meeting on Air Travel by Persons Who Use Wheelchairs, U.S. Department of Transportation, March 24, 2022, <https://www.regulations.gov/comment/DOT-OST-2022-0014-0002>

ⁱⁱⁱ United States Government Accountability Office Report, 2022, <https://www.gao.gov/assets/gao-20-258.pdf>