



Make today a breakthrough.

June 12, 2023

The Honorable Sam Graves, Chairman
Transportation & Infrastructure Committee
U.S. House of Representatives
Washington, DC 20515

The Honorable Rick Larsen, Ranking Member
Transportation & Infrastructure Committee
U.S. House of Representatives
Washington, DC 20515

The Honorable Garret Graves, Chairman
T&I Aviation Subcommittee
U.S. House of Representatives
Washington, DC 20515

The Honorable Steve Cohen, Ranking Member
T&I Aviation Subcommittee
U.S. House of Representatives
Washington, DC 20515

Re: Disability Provisions and Further Needs in the U.S. House FAA Reauthorization Bill

Dear Chairmen Sam Graves and Garret Graves and Ranking Members Larsen and Cohen,

On behalf of air passengers with spinal muscular atrophy (SMA), many of whom fly with a power wheelchair, Cure SMA appreciates that your Securing Growth and Robust Leadership in American Aviation Act ([H.R. 3935](#)) includes provisions to help address air travel challenges faced by passengers with SMA and other disabilities. While the disability-related provisions included in H.R. 3935 are meaningful, **we respectfully ask that you strengthen the training and accessibility standard provisions to improve the air travel experience for people with disabilities.**

SMA is a neurodegenerative disease that impacts physical strength, which can lead 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 breathing. While air travel may represent the most obvious option for work or personal travel, due to distance, many adults with SMA and families with children with SMA avoid or only reluctantly travel by airplane due to persistent challenges such as lost or damaged wheelchairs, injuries during transfers in and out of the aircraft seats, inaccessible lavatories, and an overall experience that is stressful, humiliating, and, sometimes, dehumanizing. *"When the pilot says, 'sit back, relax, and enjoy the flight', that ought to refer to everyone!"* said **a mother of a child with SMA**. Cure SMA highlighted air travel challenges faced by the SMA community in a national [report](#) that we shared with Congress in February.

Cure SMA and the SMA community are grateful that your legislation recognizes the need to improve safety and increase accessibility for air travelers with SMA and other disabilities. We appreciate that the legislation includes several Cure SMA-supported provisions, including **Sec. 712**, to publish cargo hold dimensions and conduct technical and economic feasibility studies for accommodating passengers in wheelchairs in the main cabin; **Sec. 713**, to collect additional data on the nature of and resolution of disability complaints; and **Sec. 707**, to extend the federal advisory committee aimed at improving air travel for people with disabilities. H.R. 3935 also includes other disability provisions related to lithium-ion batteries, codifying the passengers with disabilities bill of rights, and ensuring website, kiosk, and software application accessibility. **With appreciation for these disability items, the SMA community respectfully asks that you provide greater certainty to air travelers with SMA and other disabilities by strengthening the provisions related to training and accessibility standards.**



Individuals with SMA and their families report a significant lack of knowledge, training, proper equipment, and consideration by airport and airline staff during all aspects of the air travel experience. *“Training all airline employees on proper handling of wheelchairs and disability awareness would help improve the air travel experience for people with disabilities,”* said an **adult with SMA** featured in Cure SMA’s 2023 report. To help increase disability awareness and knowledge, H.R. 3935 codifies the passengers with disabilities bill of rights and requires airlines to ensure that their employees or contractors are trained in the provisions and protections included in the bill of rights. However, many individuals with SMA point to a lack of hand-on-training and proper equipment as the primary reasons they were dropped or injured during seat transfers or why their wheelchair was damaged. **Cure SMA respectfully asks that you enhance the training provisions in the final legislation by requiring hands-on-training related to boarding and deplaning a passenger who uses a wheelchair and for stowage of wheelchairs and other mobility devices, such as scooters.** In addition, airline personnel, including contractors, who are responsible for these duties should be required to regularly demonstrate proficiency in these tasks. Hands-on training and regular certification, as recommended in our national report, will alleviate many challenges currently faced by air passengers with SMA who travel in wheelchairs.

Cure SMA appreciates the steps your legislation takes toward the SMA community’s highest priority: allowing individuals to use their own wheelchair as their in-cabin seat. The technical and economic feasibility studies (Sec. 712) and the accessibility report (Sec. 714) to determine how personal wheelchairs can be safely secured in the passenger seating areas of airplane are important steps. **Along with these studies and reports, we also respectfully ask you to support short-term accessibility improvements of aircraft and airports.** Airlines and airports can take meaningful steps in the short-term to help improve accessibility for air passengers who use wheelchairs, such as additional elevators and wheelchair stowage lifts at airports and on-board wheelchairs and other accessible standards that can be incorporated into existing aircraft to improve the air travel experience for passengers with wheelchairs.

Thank you again for your efforts to improve the air travel experience for people with SMA and other disabilities. Cure SMA and our network of supporters from across the country look forward to working with you and your staff to strengthen and finalize the disability provisions in the final FAA reauthorization bill. For more information, your staff can contact Maynard Friesz, Cure SMA Vice President for Policy and Advocacy, at maynard.friesz@curesma.org or 202-871-8004, or Sarah Bellish, Cure SMA Advocacy Manager, at sarah.bellish@curesma.org or 202-871-8005.

Sincerely,

Kenneth Hobby
President
Cure SMA

Maynard Friesz
Vice President of Policy & Advocacy
Cure SMA

Cc: Members of the U.S. House Transportation and Infrastructure Committee