



Make today a breakthrough.

May 10, 2023

The Honorable Tammy Duckworth
United States Senate
Washington DC 20510

The Honorable John Thune
United States Senate
Washington DC 20510

The Honorable Steve Cohen
United States House of Representatives
Washington DC 20515

The Honorable Pete Stauber
United States House of Representatives
Washington DC 20515

Dear Senators Duckworth and Thune and Representatives Cohen and Stauber,

As the leading national organization that represents individuals with spinal muscular atrophy (SMA), a neuromuscular disease that impacts physical strength, **Cure SMA is pleased to support the Mobility Aids On Board Improve Lives and Empower All (MOBILE) Act.** Your legislation would help address the number one concern raised by air passengers with SMA: damaged or lost wheelchairs.

Due to a lack of physical strength, most individuals with SMA utilize customized power wheelchairs. These powerchairs are critical to the health, wellbeing, and independence of these individuals with SMA, and going without them for even a few hours can be detrimental. Cure SMA's 2023 ["The Good \(but mostly\) Bad and Ugly of Air Travel for Individuals with Spinal Muscular Atrophy"](#) report found that the air travel experience remains "*bad and ugly*" for far too many individuals and families with SMA, especially related to wheelchair damage. "*My chair was damaged to the point I couldn't function in it. It was not able to go up or down or recline which I use to breathe right. It was not able to drive far without needing a break. I was in pain for 8 months while it underwent repair,*" said **an adult with SMA**. As a result, many adults with SMA and families with children with SMA avoid or only reluctantly travel by airplane.

Your Mobility Aids On Board Improve Lives and Empower All (MOBILE) Act would help address the common wheelchair damage challenge and make air travel more accessible for people with SMA and other disabilities. The MOBILE Act would empower passengers who use power wheelchairs and other mobility devices by, among other things, requiring the U.S. Department of Transportation (DOT) to publish the dimensions of cargo holds and policies for traveling with a wheelchair as well as developing a plan to research and evaluate the technical and economic feasibility of accommodating passengers with their wheelchairs in the main cabin during flight. Knowing the cargo door dimensions can help to avoid damaging power wheelchairs. One **adult with SMA** shared that his powerchair was laid forward, breaking off the



armrests and joystick to his custom power chair. This could have been avoided if he knew his chair was too tall to fit in the upright position.

Cure SMA and our network of supporters from across the country look forward to working with you and your staff to ensure that the MOBILE Act is included in the next Federal Aviation Administration 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 sarahbellish@curesma.org or 202-871-8005.

Sincerely,

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

Kenneth Hobby,
President
Cure SMA