



Make today a breakthrough.

February 22, 2021

The Honorable Tammy Baldwin
United States Senate
709 Hart Senate Office Building
Washington DC 20510-4903

The Honorable Jim Langevin
U.S. House of Representatives
2077 Rayburn House Office Building
Washington DC 20515

Dear Senator Baldwin and Representative Langevin,

As the leading national organization that represents individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), **Cure SMA is pleased to support your Air Carrier Access Amendments Act legislation to remove existing barriers and improve air travel accessibility for individuals with SMA and other disabilities.**

Despite the enormous progress our country has made in promoting equal and accessible transportation options for Americans, significant barriers remain for individuals with SMA and other disabilities in accessing air travel. Individuals with SMA who use wheelchairs, especially power chairs, often avoid or experience unpleasant, sometimes unsafe, air travel due to inaccessible air cabins and other challenges that you documented in the Findings section of the legislation (Sec. 2).

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. The family shared their challenging travel experiences with the national committee that is studying the feasibility of wheelchair restraint systems in passenger aircraft. An adult with SMA from Illinois described how the inconsistent handling of wheelchairs to the cargo hold and inability to provide communication directly to those responsible for stowage adds to the stress of an already stressful travel experience. Other individuals with SMA have described the often, unsafe transfers to and from the aisle chair used on the plane. These unequal and unjust experiences require action by Congress to mitigate and to ensure existing law and standards are modernized to meet the needs of all air travelers, including those with disabilities.



Your legislation represents a significant step forward in making air travel more accessible and equal for individuals with SMA and other disabilities. The Air Carrier Access Amendments Act requires air carriers to provide their goods, services, and facilities in the most integrated setting appropriate, enhances the air travel complaint process for people with disabilities to include additional air carriers responsibilities and greater U.S. Department of Transportation oversight, and directs the U.S. Access Board to set minimum standards to ensure the accessible design of aircraft, including lavatories, seating accommodations, video displays, and boarding and deplaning equipment. These changes will improve the air travel experience and ensure equal access for all travelers.

Breaking down transportation barriers and making air travel more accessible are top priorities for the SMA community. Cure SMA and our network of supporters across the country look forward to working with you and your staff to help ensure this important legislation is approved by the 117th Congress. For more information, your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004.

Sincerely,

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