



Make today a breakthrough.

October 11, 2023

The Honorable Maggie Hassan
United States Senate
324 Hart Senate Office Building
Washington DC 20510

The Honorable Dean Phillips
United States House of Representatives
2452 Rayburn House Office Building
Washington DC 20515

Dear Senator Hassan and Representative Phillips,

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 legislation to require universal changing stations at U.S. airports.** This simple improvement would help to ensure that airport bathrooms are accessible for all children and adults with SMA and other disabilities.

SMA is a progressive neurodegenerative disease that robs individuals of physical strength and impacts their ability to walk, eat independently, and perform other essential functions. Many individuals with SMA may utilize a power wheelchair for their mobility and need the assistance of a personal care attendant (PCA) to assist with wheelchair transfers, toileting, and other activities of daily living.

Individuals with SMA and their families rely on air travel to participate in clinical trials, attend family functions and vacations, and for work and school-related activities. Despite disability laws and airport improvements, many individuals with SMA still face challenges when using airport bathrooms. An **adult with SMA** who requires the assistance of a caregiver described indignities he has faced when bathrooms are not designed with a person with disability in mind. *"I have had many experiences where public accommodations were not sufficient, and the only available surface large enough was the floor. Floors are not comfortable or hygienic and provide unnecessary discomfort and risk of harm or infection."* A **mother of a school-aged child with SMA** experienced a similar situation. *"I was faced with the dilemma of changing my son on the dirty, wet floor of the bathroom, changing him quickly and discreetly,"* she said. *"It's unsanitary, unsafe, undignified, and unnecessary."*

Your legislation would require that every medium and large hub airport includes a universal changing station that is large and strong enough to accommodate an adult-sized person and that includes a safety rail and straps. This improvement is especially important given many air passengers with SMA rely solely on airport bathrooms since most aircraft do not have accessible bathrooms. Cure SMA shared numerous stories in its [Good, Bad, and Ugly of Air Travel for Individuals with SMA](#) report about individuals with SMA dehydrating and fasting several hours before their flights. *"An accessible airport bathroom with an adult changing station would prevent having to change on a dirty bathroom floor,"* said an **adult with SMA**.



Cure SMA appreciates your leadership and efforts to include this sensible legislation in the final Federal Aviation Administration (FAA) Reauthorization bill before Congress. Your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at 202-871-8004 or maynard.friesz@curesma.org if they have questions or need additional information.

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
Cure SMA