



Make today a breakthrough.

February 8, 2021

The Honorable Pete Buttigieg
Secretary of Transportation
U.S. Department of Transportation
1200 New Jersey Ave SE
Washington, DC 20590

Dear Secretary Buttigieg:

As the leading national organization that represents individuals with spinal muscular atrophy (SMA), a neuromuscular disease, **Cure SMA commends the U.S. Department of Transportation (DOT) for releasing a Draft Strategic Plan on Accessible Transportation that recognizes the transportation barriers that exists for people with disabilities.**ⁱ Cure SMA supports the goals outlined in the draft plan for improving accessibility across all modes of transportation and urges the DOT to further prioritize its goals and objectives around accessible air travel.

Like all Americans, individuals with SMA rely on transportation for all aspects of their lives, from accessing healthcare, education, and employment to fully participating in and contributing to their communities. Because many people with SMA utilize a wheelchair or other device for mobility, it is imperative that all existing and future modes of transportation are accessible and operate to meet the needs of individuals with disabilities. Unfortunately, transportation barriers remain prevalent in transportation modes despite the mandate of and the progress since the Americans with Disabilities Act (ADA).

The DOT's draft strategic plan signals that the mobility of people with SMA and other disabilities is a high national priority. Outlining specific goals, objectives, and examples represents a strong foundation that has the potential to yield immediate and future results in removing transportation barriers and expanding accessible transportation options. Overall, the Department's draft strategic plan includes many of Cure SMA's own priorities related to transportation.ⁱⁱ Cure SMA provides feedback and recommendations in the following areas of the DOT strategic plan.

RECOMMENDATIONS

- **Identify Transportation Accessibility Point Person to Monitor, Implement and Report on Strategic Plan:** The Draft Strategic Plan on Accessible Transportation contains numerous informed goals, objectives, and strategies to improve transportation accessibility for individuals with disabilities. The DOT must ensure the strategic plan is implemented and results are tracked and reported to the public, especially to the disability community.
 - ***Cure SMA recommends that the DOT identify a management-level point person (i.e., accessibility czar) to monitor and initiate progress within***

the DOT and to engage and inform external stakeholders, including people with disabilities and organizations that represent individuals with disabilities.

- **Strengthen Strategies Around Accessible 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. People with SMA must check their wheelchair with no confidence or assurance that their lifeline to independence and mobility will arrive undamaged. A Cure SMA California family described all the precautions they take to protect the powerchair of their son with SMA, from disassembling breakable parts (i.e., joystick) and bubble-wrapping the chair to tagging it with visual instructions for moving and lifting, including a personal plea to *take good care* of the equipment. An adult with SMA from Illinois described how the inconsistent handling of wheelchairs to the cargo hold and inability to provide communication to those responsible for stowage adds to the stress of an already stressful travel experience. Finally, individuals with SMA have described the often, unsafe transfers to and from the aisle chair used on the plane.
 - ***Cure SMA recommends that the DOT expand upon strategies 5.1.3 and 5.1.4 to issue and enforce uniform guidance, especially related to wheelchair handling and emergency evacuation procedures, to improve air travel accessibility and safety of air travelers with SMA and other disabilities.***
 - ***Cure SMA recommends that the DOT accelerate the consideration and implementation of in-cabin wheelchair restraint systems in passenger aircraft to allow individuals with disabilities to roll onto the plane with their own wheelchair.***
- **Increase Accessibility and Opportunities to Pursue Driver Licensure:** Adults and young adults with SMA who want to operate their own personal vehicle continue to face challenges from discrimination by state driver licensing agencies (SDLA) staff and inaccessible SDLA locations. In addition, the cost to convert a personal vehicle into an accessible vehicle continues to be cost prohibitive for many individuals with SMA and other disabilities. For one adult with SMA from Texas, the process to get his driver's license took 3 years, from applying for and securing funds to retrofit his vehicle to the actual driver's training and license test. While his SDLA representative had never seen an accessible vehicle with joystick controls, the actual testing process was standard and went smoothly. Securing his license has given this 34-year-old adult with SMA increased independence and flexibility in where he lives and works, which previously needed to be in proximity of a bus line.
 - ***Cure SMA recommends that the DOT conduct a thorough analysis of SDLA locations to identify barriers and solutions to improve access for people with disabilities. In addition, the DOT should report to Congress the feasibility of developing a national accessibility program to help***

assist individuals with disabilities in converting vehicles into accessible vehicles, a significant barrier for individuals with disabilities and their ability to secure a driver's license.

SUPPORT FEEDBACK

Cure SMA strongly supports the following strategic goals, strategies, and objectives:

- Cure SMA strongly supports the DOT's guiding principle around stakeholder engagement and encourages regular stakeholder opportunities with the disability community.
- Cure SMA strongly supports the DOT's efforts to ensure automated vehicles and other new technologies are designed with the needs of people with disabilities in mind.
- Cure SMA strongly supports the DOT's recommendations for uniform accessibility standards and tools around pedestrian facilities, transportation technologies, and multimodal network data quality.
- Cure SMA strongly supports DOT's oversight and enforcement provisions to ensure transportation systems comply with existing law and standards.
- Cure SMA strongly supports the DOT's interest in new research into technologies that have the potential to increase accessibility in transportation system.

Thank you for your attention to the transportation needs and challenges facing individuals with SMA and their families. If your team has questions or needs additional information, please have them contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at 202-871-8004 or maynard.friesz@curesma.org.

Sincerely,



Kenneth Hobby
President
Cure SMA



Maynard Friesz
Vice President of Policy & Advocacy
Cure SMA

ⁱ U.S. Department of Transportation's Strategic Plan on Accessible Transportation, January 2021, <https://www.transportation.gov/mission/accessibility/strategic-plan-accessible-transportation>

ⁱⁱ Cure SMA Transportation Principles and Priorities, 2021, <https://www.curesma.org/wp-content/uploads/2021/01/Cure-SMA-Transportation-Principles-and-Priorities.pdf>