



Make today a breakthrough.

March 23, 2021

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

Dear 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 the Disability Access to Transportation Act** that is aimed at promoting accessible community transportation options for individuals with SMA and other disabilities.

Many people with SMA utilize a mobility device, such as a power wheelchair, because SMA robs individuals of physical strength and can take away their ability to walk. Individuals with SMA rely on accessible transportation options to access their community and to participate in regular activities of daily living, such as going to school, work, or other events and activities. Unfortunately, individuals with SMA and other disabilities often face regular barriers and unequal transportation options.

A 34-year-old man with SMA found that driving his power wheelchair 45 minutes to and from work was his fastest and most reliable transportation option. He did not live on a bus route and the paratransit service for his under 4-mile, one-way trip could take up to two hours. Instead, he rode his wheelchair in the bike lane of a busy city street each way to work. "Thank goodness, nothing happened, but it could of. I was out there with cars and there was no barrier between me and them," he said. The bike lane was his only option given his route included several sidewalk curbs and pathway barriers. "My wheelchair is pretty beat up," he said in describing the wear and tear on his chair. "The wheels jiggle whenever I get it to a certain speed, and I've gone through several battery and tire replacements."

A 43-year-old elementary school teacher with SMA encountered a similar transportation challenge. Despite living in a major metropolitan city, she described feeling like she lived in a transportation desert given none of the available transportation options made sense for her situation. As a teacher, she needed to arrive at school each day by 7:20 a.m. If she took paratransit, she would need to book a 5:20 a.m. pick-up to guarantee that she arrived on-time and before her students. The public transit options would have taken nearly as long with four transfer points between buses and light rail lines. "It is incredibly frustrating," she said when comparing her accessible transportation options to other places she has visited, including London and New York City. "Having the freedom to step out of your office or a



concert and hail an accessible cab is a gift.” Her community recently started a paratransit pilot with Uber that has greatly improved options and convenience.

The Disability Access to Transportation Act (H.R.1697) would help expand reliable and convenient community transportation options for people with disabilities, including individuals with SMA. The legislation would provide states with additional resources through the Federal Transit Administration’s Section 5310 Formula Grant Program to fund rural and urban projects aimed at enhancing mobility of seniors and individuals with disabilities. Past funds have allowed communities and local organizations to purchase accessible transit vehicles, implement wheelchair lifts, establish volunteer driver programs, and install way-finding technology. In addition, the Disability Access to Transportation Act would establish a pilot program focused on collecting and analyzing data to better meet the needs of users and another pilot to improve convenience and reduce the need for multiple stops for paratransit services. Finally, the legislation would ensure the U.S. Department of Transportation adopts accessibility guidelines for trails, sidewalks, pedestrian facilities, and shared-use paths for bicyclists and pedestrians, including pedestrians with disabilities. These guidelines would promote accessibility by standardizing, for example, the width and slope of curb ramps and shared paths.

Cure SMA is pleased to support the Disability Access to Transportation Act as it continues the vision and mandate of the Americans with Disabilities Act of equality of opportunity, full participation, independent living, and economic self-sufficiency for Americans with disabilities. Cure SMA and our network of supporters across the country look forward to working with you and your staff to help ensure this 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