



Make today a breakthrough.

August 4, 2021

The Honorable Bob Casey
United States Senate
Washington DC 20510

The Honorable Susan Collins
United States Senate
Washington DC 20510

The Honorable Maggie Hassan
United States Senate
Washington DC 20510

The Honorable Kevin Cramer
United States Senate
Washington DC 20510

Dear Senators Casey, Hassan, Collins, and Cramer:

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 21st Century Assistive Technology Act (S. 2401), the bipartisan legislation you sponsored to expand knowledge of and access to assistive technology (AT) devices and services for individuals with SMA and other disabilities.**

SMA is a degenerative disease that robs individuals of physical strength, greatly impacting their ability to walk, eat, and perform other essential functions of everyday life. People with SMA often utilize AT devices, such as mobility aides, adaptive utensils, or eye-gaze communication systems, to assist them with an activity of daily living.

For example, a 27-year-old with SMA has required a wheelchair since he was a child. Beginning in high school, his upper body strength declined where he was unable to eat independently without assistance. For several years, he would *“get creative”* to retain more independence. *“I would have friends put a cup with a lid in front of me where I rested my hand so it was closer to my mouth. They would then put my sandwich in my hand so I could eat. It wasn’t great, but it provided me with some independence,”* he recalled. But then he learned about, and later received, a robotic arm with three mechanical fingers that attached to his wheelchair. Using a joystick, he controls the arm and fingers to eat and drink independently as well as perform other routine functions, such as adjusting his glasses or picking up small objects. *“I couldn’t live without the device. It has been a life-changing technology for me, giving me the independence that I had yearned for so many years.”*

The 21st Century Assistive Technology Act would help individuals with SMA and other disabilities access AT devices and services aimed at promoting independence and full participation in education, employment, and daily activities. The legislation would expand the State Grant for Assistive Technology Program that helps states provide training and education and improve access to AT devices and services. The 21st Century Assistive Technology Act would also invest in data collection and projects of national significance to



measure gaps in accessing assistive technology, promote greater collaboration among state disability-focused agencies, and address the AT devices and services needs of youth with disabilities who are transitioning into adulthood.

Cure SMA was pleased the U.S. Senate Health, Education, Labor, and Pensions Committee recently approved the 21st Century Assistive Technology Act (S. 2401).

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 finalized by the 117th Congress so that individuals with SMA and other disabilities have greater knowledge about and access to AT devices and services. 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