



Make today a breakthrough.

April 10, 2024

The Honorable Bob Casey
The Honorable Tim Kaine
The Honorable Tammy Baldwin
United States Senate
Washington DC 20510

Dear Senators Casey, Kaine, and Baldwin,

Cure SMA is pleased to support the Long-term Care Workforce Support Act. Your legislation would help address the caregiving crisis faced by individuals with spinal muscular atrophy (SMA) and other disabilities by investing in public-private strategies to expand caregiving services and strengthen the long-term care workforce.

Access to caregiving is among the highest priorities of individuals with SMA, a neuromuscular disease that impacts the muscles used for activities such as walking, eating, and breathing. Due to muscle loss and weakness associated with SMA, many children and adults with SMA require assistance with everyday activities such as getting out of bed, toileting, grooming, and transferring to their power wheelchair. On average, individuals with SMA require 1-3 caregivers and more than 100 caregiving hours a week to maintain their health and independence, according to a 2024 Cure SMA caregiving [report](#). *“Without caregivers, I would be confined to a nursing home, unable to be employed, never having attended school, and unable to be a spouse,”* said a **Virginia man with SMA**.

Unfortunately, most individuals with SMA face barriers in accessing caregivers and caregiving services. *“As my disease has progressed, I have required increasingly more personal care assistance to get through the day,”* said a **working adult with SMA from Wisconsin**. *“My insurance does not cover the cost of my personal care workers, and I continue to be in a situation where I cannot afford the care that I need.”* Cure SMA’s caregiving report found that 86 percent of individuals with SMA struggled to find caregivers and 37 percent received far fewer caregiving hours through their state than they needed to meet their daily living needs. The shortage of care workers and caregiving hours greatly impacts the independence and community participation of individuals with SMA. *“I would love to move out and be on my own, just like any other 25-year-old wants to be. However, because I can’t get enough care hours, I do not see a future where I would be able to be independent and live on my own,”* said a **young adult with SMA**.


The Long-term Care Workforce Support Act would help address the twin struggles of not receiving enough caregiving hours and difficulty in finding paid caregivers. Your legislation would provide states with additional federal matching funds to expand home and community-based services (HCBS), eliminate HCBS waiting lists, and invest in the care workforce through higher reimbursement rates. *“I do not know how long my husband and I can sustain doing our care by ourselves on the weekends. We simply need more help but we’re not getting it,”* said a **Pennsylvania woman with SMA** who has




struggled for two years to find weekend caregivers. In addition, your legislation would provide grants to public and private entities to explore strategies for strengthening and expanding the long-term care workforce in urban and rural areas through improved compensation, specialized training, and career advancement. Finally, your legislation includes protections for spouses and care workers, requires data collection on caregiving gaps and needs, and implements oversight and evaluation procedures to help achieve the goals of the legislation.

Cure SMA and the entire SMA community appreciate your leadership and efforts to expand caregiving services and strengthen the long-term care workforce for individuals with SMA and other disabilities. Cure SMA looks forward to working with you to raise awareness about the caregiving needs and challenges of people with disabilities and older adults and to grow support for solutions, such as the ones you've outlined in your legislation. 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,


Kenneth Hobby
President
Cure SMA


Maynard Friesz
Vice President of Policy
Cure SMA