



July 1, 2026

The Honorable Tim Kaine
United States Senate
231 Russell Senate Office Building
Washington, DC 20510

Dear Senator Kaine:

As the leading national organization representing individuals with spinal muscular atrophy (SMA) and their families, **Cure SMA is pleased to support your Supporting Our Direct Care Workforce and Family Caregivers Act.** Many children and adults with SMA rely on the support of direct care workers and paid and unpaid family caregivers for their health, independence, and community participation, and your legislation would help ensure these caregivers are available, well-trained, and supported.

SMA is a rare neurodegenerative disease that causes severe muscle weakness and loss of motor function, affecting movement, breathing, and everyday life. Most individuals with SMA, including Virginia residents you met during Cure SMA's Hill Day, rely on one or more caregivers to assist with activities of daily living, including eating, bathing, dressing, mobility, and respiratory care. As one **adult with SMA** shared, *"As my disease has progressed, I have required increasingly more personal care assistance to get through the day."*

Unfortunately, the direct care workforce shortage is one of the most pressing challenges facing the SMA community today. Cure SMA's 2025 State of SMA report found that 87% of individuals with SMA rely on one or more caregivers, yet 92% of respondents said it is extremely difficult or a little difficult to find and retain paid caregivers. As **one adult with SMA** shared in the report, *"The ability to find and maintain caregivers is a tremendous burden.... I have grave concerns as my spouse ages about continuing to receive adequate care in my home."*ⁱⁱ Direct care workforce shortages contribute directly to gaps in care, which can lead to missed work or school, delayed medical care, or preventable health complications.

The Supporting Our Direct Care Workforce and Family Caregivers Act takes meaningful steps to address this caregiving crisis. Your legislation would establish a national technical assistance center and fund targeted grants to help expand the recruitment, training, and retention of direct care professionals and family caregivers who are vital to people with SMA and other disabilities. Cure SMA is especially pleased that your legislation recognizes the importance of direct care workers and family caregivers who are employed through Medicaid self-directed care. Your legislation authorizes separate grants aimed at these key caregivers. Cure SMA recently issued a legislative brief highlighting the value of self-directed care and paid family caregiving in light of recent state and federal policy developments.ⁱⁱⁱ

Children and adults with SMA are accomplishing great things in their schools, workplaces, and communities. But their ability to thrive and contribute to their families and communities is often tied to their ability to access Medicaid home care and the trained and reliable caregivers who provide these services. Your legislation would help expand the pool of these essential workers, which is why Cure SMA strongly supports your Supporting Our Direct Care Workforce and



Family Caregivers Act. We look forward to working with your staff to help advance this important legislation through Congress.

Thank you again for your leadership on this issue and for your continued commitment to the SMA community. Please do not hesitate to contact Cure SMA with any questions. Your staff may reach Maynard Friesz, Vice President for Policy and Advocacy, at 202-871-8004 or maynard.friesz@curesma.org.

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, Policy & Advocacy
Cure SMA

ⁱ Stuck Inside National Caregiving Report, Cure SMA, https://www.curesma.org/wp-content/uploads/2024/01/Advocacy_Report_Stuck_Inside_vFnl_Web.pdf#page=5

ⁱⁱ State of SMA Report, Cure SMA, https://www.curesma.org/wp-content/uploads/2026/05/2025_State_of_SMA_Report_vWeb.pdf#page=35

ⁱⁱⁱ Protect Medicaid Home Care for People with SMA, Cure SMA, <https://d3dkdvqff0zqx.cloudfront.net/groups/curesma/attachments/Cure%20SMA%20Protect%20Home%20Care%20Legislative%20Brief.pdf>