



Make today a breakthrough.

February 3, 2025

The Honorable Debbie Dingell
United States House of Representatives
102 Cannon House Office Building
Washington DC 20515

Dear Representative Dingell:

On behalf of individuals with spinal muscular atrophy (SMA) and their family caregivers, **Cure SMA is pleased to endorse your Family Caregiver Awareness, Resources, and Education (CARE) Partnerships Act.** Your legislation would help support the health, well-being, and preparedness of family caregivers who play such a critical role in the lives of individuals with SMA and other disabilities or chronic health conditions.

SMA is a progressive neurodegenerative disease that attacks the nervous system and destroys muscles used for everyday living activities, such as walking, eating, and breathing. Due to significant muscle decline and motor function loss caused by SMA, individuals with SMA require, on average, 100+ hours of caregiving assistance each week. Nearly all individuals with SMA rely on a parent, spouse or other family caregiver to assist with wheelchair transfers, bathroom support, and other routine daily activities.

Family caregivers of individuals with SMA provide about 45 hours per week in unpaid caregiving services, according to Cure SMA's [Stuck Inside](#) national caregiving report. Their caregiving duties are typically on top of their work schedules and other daily responsibilities, which can contribute to their own declines in physical and mental health. Many individuals with SMA worry about their independence if something happens to their family caregiver who may represent their primary or only backup support. *"My parents are getting older and the physical and mental aspects of caregiving is getting more challenging for them,"* said an adult woman with SMA. Another adult with SMA said, *"I do worry about the level of care my parents can provide as they get older."* Cure SMA found that 20 percent of all SMA caregivers are over the age of 60.

The CARE Partnerships Act highlights the important and rewarding role of family caregivers while also recognizing the heavy toll caregiving can have on their own physical and mental health. Your legislation would create a network of centers of excellence to increase awareness about health risks associated with caregiving, educate family caregivers about available supports, develop best practices to benefit caregiver health, and evaluate the effectiveness of these public health strategies through data collection and analysis. **If enacted, your legislation would help address one of the caregiving challenges identified by individuals with SMA.**



In addition to supporting family caregivers, Cure SMA remains committed and focused on strengthening access to caregiving services available through Medicaid home and community-based services (HCBS). Many individuals with SMA also require the daily assistance of personal care attendants paid for through Medicaid. Cure SMA found that [86 percent](#) of individuals with SMA and their families struggled to find caregivers and [62 percent](#) reported difficulty retaining caregivers. In addition, many individuals with SMA reported receiving fewer paid caregiving hours from Medicaid than what they need to meet their daily and weekly needs. Cure SMA will continue to support efforts to strengthen Medicaid and HCBS caregiving supports as well as family caregivers who often fill the gap between the paid caregiving hours they receive versus what they need.

Cure SMA and our supporters in Michigan and across the country strongly support the CARE Partnership Act and other efforts to support family caregivers and strengthen access to paid caregiving services. Your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004 should you or they have questions or need additional information. Thank you.

Sincerely,

A handwritten signature in black ink that reads "K. A. Hobby".

Kenneth Hobby
President

A handwritten signature in black ink that reads "Maynard Friesz".

Maynard Friesz
Vice President of Policy & Advocacy