



Make today a breakthrough.

March 14, 2024

Dear Minnesota Legislative Leaders:

On behalf of Minnesota residents with a neuromuscular disease known as spinal muscular atrophy (SMA), **Cure SMA respectfully asks that you help address the caregiving challenges faced by individuals with SMA and their families.** SMA robs individuals of physical strength and impacts their ability to walk, eat independently, and perform other essential functions. Many individuals with SMA utilize personal care attendants (PCAs) or other direct care workers to assist in their daily lives. *"I rely on PCAs for all of my activities of daily living, including bathing, transfers, grooming, cooking, dressing, transportation, and bathroom breaks,"* said an **adult with SMA from Minnesota.**

Despite the importance of caregiving, **most individuals with SMA face significant barriers to accessing caregiving services.** Cure SMA chronicled the caregiving challenges faced by individuals and families with SMA from Minnesota and the rest of the country in a 2024 national [caregiving report](#). The SMA community's top concerns are related to difficulties in recruiting and retaining paid caregivers. *"Finding and maintaining caregivers is the ABSOLUTE HARDEST,"* said a **Minnesota adult with SMA** who is featured in the report. Overall, 86 percent of individuals with SMA and their families struggled to find caregivers and 62 percent reported difficulty retaining caregivers. *"Without caregivers, I am unable to participate in most activities of daily living and definitely cannot have a social life or engage in enrichment activities,"* said a **young adult with SMA from Minnesota.**

Cure SMA and the SMA community seeks your support for legislation to strengthen the direct care workforce through increased wages, benefits, training, and career mobility. *"PCA pay is often less than what caregivers can get from regular babysitting positions,"* said a person with SMA featured in Cure SMA's 2024 report. Another individual with SMA described caregiver pay as being *"tragically low,"* noting that caregivers often receive *"less than wages paid to fast food workers."* **Cure SMA strongly supports efforts by the Minnesota Legislature to promote access to caregiving services by investing in the direct care workforce.**

Thank you for supporting the caregiving needs of individuals with SMA and other disabilities. 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