



Make today a breakthrough.

February 13, 2024

The Honorable Brett Guthrie
Chairman, Health Subcommittee
Energy and Commerce Committee
U.S. House of Representatives
Washington, DC 20515

The Honorable Anna Eshoo
Ranking Member, Health Subcommittee
Energy and Commerce Committee
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Guthrie and Ranking Member Eshoo,

In advance of your hearing to examine ways to support patients and caregivers, **Cure SMA is pleased to preview findings from an upcoming national report on the caregiving needs of children and adults with spinal muscular atrophy (SMA).** We hope this information will help inform your hearing and future legislation to address the caregiving crisis faced by families impacted by SMA and other disabilities across the country.

SMA is a rare degenerative neuromuscular disease that robs individuals of their physical strength, greatly impacting their ability to walk, sit without support, transfer independently, and perform other essential functions of everyday life. Cure SMA is the national organization that represents individuals with SMA and their families in your districts and across the country. **On Friday, National Caregivers Day, Cure SMA will release a [national report](#) that chronicles the caregiving needs and challenges of people with SMA,** many of whom require in-home caregivers, whether a paid personal care attendant (PCA) or family caregiver, to assist in their daily lives. *"I rely on caregivers for all of my activities of daily living, including bathing, transfers, grooming, cooking, dressing, transportation, and bathroom breaks,"* said **an adult with SMA.**

Individuals with SMA who require in-home support reported needing 100+ caregiving hours a week, on average, to assist with their activities of daily living. Most individuals with SMA depend on 1-3 caregivers for this essential caregiving assistance, of which half are paid through Medicaid or other sources and half are uncompensated family caregivers. *"I receive 42 hours a week of caregiving hours through the state, which is not nearly enough for what I need. It's why I still live at home with my parents, who assist me during hours when I don't have paid caregiving,"* said **an adult man with SMA.** Another **adult with SMA** said, *"I only get about 6 hours per day of paid caregiving, which essentially covers a morning caregiver to come and shower me and get me into my wheelchair so I can go to work and then one to come at night to put me into bed. The lack of hours means I am without paid support during the day for toileting and eating."*

According to Cure SMA's upcoming caregiving report, **79 percent of individuals with SMA relied on at least one unpaid family caregiver,** which can include parents, grandparents, partners, siblings, and other relatives. Some family caregivers play a primary role in their loved one's lives, providing daily and weekend help with everything from transferring in and out of bed and wheelchairs to assistance with dressing, grooming, meal preparation, and bathroom support. *"I couldn't do it without the help I get from my spouse,"* said a **married adult with SMA.** Other family caregivers serve as backup for hours uncovered by other caregivers or when the paid caregiver is unavailable. *"Because of the worker shortage, my parents often have to cover when my caregiver calls in sick or during planned days off,"* said **an adult with SMA.**



Cure SMA is pleased that the Health Subcommittee will examine the important role and needs of family caregivers. Many individuals with SMA worry about what will happen to them if their family caregiver becomes unavailable due to health, injury, or other reasons. For many adults with SMA, the challenge is even greater given the age of their family caregivers. *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, *“My mother helps me when I don’t have a PCA, but I worry about the toll it takes on her health given she is in her 60s.”*

Several studies have chronicled the detrimental health effects of family caregiving, which can include stress, depression, physical ailments, poor diets, and missing their own healthcare appointments.ⁱ Family caregivers of individuals with SMA provide, on average, about 45 hours per week in unpaid caregiving services, according to Cure SMA’s *Understanding the Caregiver Experience* report, which is significantly higher than the 23.7 hours per week of all caregivers.ⁱⁱ Respite is one strategy to help provide temporary relief to family caregivers. However, many family caregivers are unaware of or unable to access respite care in their state.ⁱⁱⁱ **Cure SMA supports the Lifespan Respite Care Program, which provides funding to states to help improve and expand the availability of respite care services for their residents.** Cure SMA supports the reauthorization and expansion of this critical program so that all family caregivers, including those who support individuals with SMA, can access these services.

We appreciate the focus on respite care at this hearing. However, the caregiving needs and challenges of the SMA community are greater and more chronic. As highlighted in our upcoming report, individuals with SMA and their families face many caregiving challenges, including:

- lack of clear information about caregiving options available in the state,
- eligibility requirements that are restrictive, penalize savings, and limit work,
- state caregiving hours do not meet actual caregiving needs,
- difficulty in recruiting and retaining direct care workers, and
- concern over the health, age, and availability of backup family caregivers.

Cure SMA encourages the Health Subcommittee to continue its important work to examine and address the challenges that are causing the caregiving crisis in this country. Cure SMA welcomes the opportunity to meet with your staff to share our report and its findings, which we hope will help inform your work in addressing the direct care workforce shortage and other caregiving challenges. Your staff can reach out to Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004, for the report or for any questions.

Sincerely,


Kenneth Hobby
President
Cure SMA


Maynard Friesz
Vice President of Policy & Advocacy
Cure SMA

Cc: Members of the U.S. House Energy and Commerce Health Subcommittee



ⁱ Physical and Mental Health Effects of Family Caregiving, NIH, 2009, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2791523/>

ⁱⁱ Caregiving in the U.S., AARP, 2020, <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>

ⁱⁱⁱ Economic consequences and lack of respite care, 1999, <https://pubmed.ncbi.nlm.nih.gov/10672749/>