cure
SMA

Make today a breakthrough.

April 15, 2020

The Honorable Nancy Pelosi
Speaker
United States House of Representatives
Washington, DC 20515

The Honorable Mitch McConnell
Majority Leader
United States Senate
Washington, DC 20510

The Honorable Kevin McCarthy
Minority Leader
United States House of Representatives
Washington, DC 20515

The Honorable Charles Schumer
Minority Leader
United States Senate
Washington, DC 20510

Dear Speaker Pelosi, Leader McConnell, Leader McCarthy, and Leader Schumer:

As the leading national organization that represents individuals and families impacted by spinal muscular atrophy (SMA), **Cure SMA urges you to include dedicated funding and provisions in the next COVID-19 package to support safe and ongoing access to in-home services and to ensure that medical care and equipment are not rationed or otherwise withheld** for Americans with pre-existing conditions due to their disability or rare disease, such as SMA.

SMA is a progressive neurodegenerative disease that can significantly impact an individual's ability to walk, swallow, and—in the most severe cases—even breathe. SMA impacts approximately 12,000 Americans and 1 in every 11,000 births in the U.S.

Individuals with SMA are at greater risk of serious illness from COVID-19 due to underlying health conditions, including respiratory issues. Cure SMA has been actively supporting the health and well-being of children and adults with SMA and their families through specialized information, webinars, and resources. The SMA community has also taken their own proactive steps for isolation and social distancing, which is part of their normal routine to restrict exposure of this fragile population during respiratory viral season.

However, based on results from a Cure SMA COVID-19 Impact Survey, more must be done to ensure the safety and care of Americans with SMA. Congress has an important role in helping to address these concerns.

Individuals with SMA often rely on community services and in-home supports, such as home health aides, physical therapy, and personal care services to maintain their health and assist in their activities of daily living. Since the outbreak of COVID-19, nearly 50% of SMA households reported changes and limitations to accessing these essential home and community-based services. One family said their *"nursing agency is struggling to provide nursing coverage."*

Several families described their essential caregiving needs and asked for *"ideas for continued care (physical therapy, occupational therapy, etc.) at home"* while another survey respondent sought *"reassurance for the opportunity to continue receiving quality care during these times."*

Several survey respondents highlighted the counter challenge of social distancing with the reliance on an outside caregiver to assist in such things as dressing, bathing, food preparation, and commuting. One family described feeling fearful while seeking answers to caregiving questions, such as: *"What are the rules regarding attendant care? Can they still come? What to do if they abandon you? How to keep everyone safe? What to do if they aren't self-isolating?"*

- **Cure SMA Recommendation:** ***Congress should provide dedicated funding for home and community-based services for individuals with SMA and others to ensure access to these essential supports and services.*** We thank Congress for including a temporary funding (FMAP) increase for Medicaid, but additional, dedicated resources must be included in the next COVID-19 package to maintain and expand home and community-based services throughout the public health crisis.

Individuals and families impacted with SMA also raised concern about their own well-being and the safety of their caregivers during this crisis. Direct support professionals, such as home health aides, nurses, and personal care attendants, regularly support multiple patients during their workday or work week. One survey respondent noted that their caregiver *"works at other facilities, such as assisted living, when they are not working for me. I am concerned about cross contamination."* In addition, many care professionals lack personal protective equipment (PPE) when they enter a home to provide their services. *"I am glad I had some masks and gloves for my caregivers for regular cold and flu. I wish we were better prepared with sanitizer and wipes and masks, as we use these regularly."* For many SMA households, the need for PPE for their caregiver is more immediate. Many respondents sought masks, gloves, antibacterial wipes, and cleaning supplies for their in-home caregivers. Some families are foregoing the caregiving services they are eligible to receive (*"no one allowed in or out of the house so no in-home nurse care")* while others are preparing back-up plans (*"if they lose caregivers during these situations.")*

- **Cure SMA Recommendation:** ***Congress should provide funding to help recruit, train, and properly equip direct support professionals throughout the COVID-19 public health emergency to ensure individuals with SMA have ongoing and safe access to home health aides, nurses, personal care attendants, and other direct support professionals.***

Some SMA households reported the unique challenge of being the primary family caregiver of a child or adult with SMA while also working in the health care field or other essential role. *"My husband is a mandatory worker and my caretaker. I'm scared if either of us got the virus. I wouldn't want to be alone in the hospital and I can't take care of myself if he got sick."* Another survey respondent said, *“I'm a nurse and I am his primary caregiver. I'm afraid I'll bring it home to him.”* One household reported that a parent who served in a public, frontline capacity took a temporary leave of absence to protect their child with SMA. *“We are hoping we can continue to pay our bills, especially the mortgage on our house.”*

- **Cure SMA Recommendation:** ***Congress must expand the Family and Medical Leave Act provisions to ensure Americans who care for individuals with SMA and other high-risk conditions receive job protection and financial support that enables them to remain at home for the duration of the pandemic.*** Family caregivers shouldn’t have to fear losing their job if they must remain home to safely care for their loved one.

Cure SMA asks that Congress use its influence and authority to ensure states exercise the emergency flexibility within Medicaid and other federal programs to use remote technologies for health appointments or benefit meetings, pay family caregiver who assist a family member with an in-home service they are otherwise eligible to receive, and work with the states, federal agencies, and health care facilities to prevent discrimination against individuals living with SMA in accessing medical care, hospital admittance, and required equipment, such as ventilators.

Finally, we would like to highlight the importance of and need for COVID-19 economic relief provisions. More than 65% of SMA households have experienced financial hardship due to COVID-19. About 8% reported having lost their jobs and nearly 9% are no longer earning money as a result of a furloughed position.

Please do not hesitate to contact Cure SMA if you have questions related to our COVID-19 SMA Community Survey. Your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004. Thank you for considering our views.

Sincerely,

K.A. Hobby	Mary Schroth	Colleen McCarthy O'Toole	Jill Jarecki
Kenneth Hobby President	Mary Schroth, M.D Chief Medical Director	Colleen McCarthy O’Toole Vice President, Family Support	Jill Jarecki, PhD Chief Scientific Officer