



Make today a breakthrough.

March 4, 2021

The Honorable Charles E. Schumer
Majority Leader
United States Senate
Washington, DC 20510

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

Dear Majority Leader Schumer and Minority Leader McConnell:

As the leading national organization that represents individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), **Cure SMA writes in strong support of Section 9817 of the American Rescue Plan Act of 2021** that would provide additional support for Medicaid home and community-based services during the COVID-19 emergency.

SMA is a progressive neurodegenerative disease that robs individuals of physical strength, taking away their ability to walk, eat, and breathe. Individuals with SMA are at greater risk of serious illness from COVID-19 due to underlying neuromuscular and respiratory muscle weakness that can be exacerbated by viral illness such as COVID-19. In addition, many individuals with SMA are in regular contact with home health aides or personal care assistants for essential care and to assist with their activities of daily living. It is critical for individuals with SMA that these Medicaid-funded home and community-based services are maintained, without interruption, and delivered in the safest manner possible during this public health emergency.

Unfortunately, individuals with SMA and their families have faced numerous, ongoing challenges related to home and community-based services during the COVID-19 pandemic. The SMA community has shared their experiences and needs during the COVID-19 pandemic through ongoing Cure SMA surveys. Regrettably, the SMA community's most recent response shows that individuals with SMA and their families confront many of the same challenges today, one year into the pandemic, that they faced during the start of the public health emergency. For example, **more than 70% of respondents still identified a shortage of personal protective equipment (PPE) and other medical supplies for them and their caregivers as their greatest worry.** To minimize exposure to COVID-19, most individuals with SMA who utilize a personal care attendant or other caregiver carry the responsibility of providing their caregiver with proper PPE and other supplies. Comments from survey respondents include: *"I have had difficulty finding gloves for caregivers and Lysol-type antibacterial wipes and spray," "it's very difficult to find nitrile gloves for my caregiver at an affordable price,"* and *"all PPE is very expensive when obtained and hurts so much financially. I just purchased a case of gloves that normally cost \$35. Now, I pay \$90 a case."* One individual with SMA shared that they were *"worried that my one and only caregiver will quit because I don't have enough PPE."*



Finding and maintaining qualified and reliable caregivers is the other consistent problem facing individuals with SMA during the COVID-19 pandemic. One respondent summed up the challenge by noting that *“personal care assistants (PCA) are being diagnosed with COVID and unable to come in. This creates an urgent situation for those living independently with the help of PCAs.”* The COVID-19 public health emergency worsened the existing challenge of finding and keeping caregivers and aides due to the direct care worker shortage. Many individuals with SMA described the regular stress and challenge in finding backup caregivers or emergency respite care.

Section 9817 of the American Rescue Plan Act of 2021 would help to mitigate some of these challenges by temporarily increasing the federal Medicaid match to states by 7.35% for enhancing, expanding, or strengthening Medicaid home and community-based services, including for home health, personal care, and rehabilitative services. These vital funds would allow states to better meet the needs of individuals with SMA and other populations who rely on care and services for independent living and activities of daily living.

On behalf of individuals with SMA and their families, Cure SMA respectfully asks that you support Section 9817 of the American Rescue Plan Act of 2021 and to ensure these vital funds are signed into law. If you have questions, 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,

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