



Make today a breakthrough.

July 10, 2023

The Honorable Bernie Sanders  
Chairman  
U.S. Senate Health, Education, Labor, and  
Pensions Committee  
Washington, DC 20510

The Honorable Bill Cassidy  
Ranking Member  
U.S. Senate Health, Education, Labor, and  
Pensions Committee  
Washington, DC 20510

The Honorable Robert P. Casey  
Member (PAHPA Lead)  
U.S. Senate Health, Education, Labor, and  
Pensions Committee  
Washington, DC 20510

The Honorable Mitt Romney  
Member (PAHPA Lead)  
U.S. Senate Health, Education, Labor, and  
Pensions Committee  
Washington, DC 20510

Dear Chairman Sanders, Ranking Member Cassidy, and Senators Casey and Romney:

As the leading organization that represents children and adults with spinal muscular atrophy (SMA), a neuromuscular disease, Cure SMA is pleased that the discussion draft of the Pandemic and All-Hazards Preparedness Act (PAHPA) includes provisions to help address the emergency and pandemic preparedness and response needs of people with SMA and other disabilities.

As we have shared in previous correspondence, individuals with SMA, many of whom utilize a power wheelchair for their mobility, worry that federal, state, and local governments are not prepared to meet their needs in times of an emergency. An adult with SMA described how she relied on social media for help during a past hurricane evacuation and another person with SMA described how she stored her backup power wheelchair in the ground level bike storage room in case electricity impacted her ability to exit her apartment building via her elevator. The SMA community urged Congress to meet the needs of people with disabilities in the next PAHPA reauthorization.

Cure SMA is pleased that the PAPH A discussion draft includes several provisions aimed at improving our country's emergency preparedness and response for people with disabilities.

- **Sec. 304:** Cure SMA fully supports the establishment of technical assistance centers to develop, evaluate, and disseminate strategies to improve health and related outcomes for at-risk individuals, including people with disabilities. Cure SMA also supports the requirement for the U.S. Department of Health and Human Services to develop guidelines to help states and localities create or modify a crisis standard of care. Cure SMA asks that this standard of care includes the ability for people with disabilities who



receive home and community-based services through Medicaid to continue to receive those needed services even when the person must temporarily relocate to a new city or state.

- **Sec. 305:** Cure SMA fully supports the changes that will ensure the national advisory committee on individuals with disabilities better represents the needs of people with disabilities and can provide recommendations to Congress and other agencies for improving disaster preparedness and response.

Cure SMA respectfully asks that you continue to look for ways to meet the needs of people with SMA and other disabilities through the next PAHPA reauthorization, including direct assistance to state and local governments to meet the immediate and unique needs of people with disabilities. Thank you for considering the views of the SMA community. Your staff can reach out to Maynard Friesz, Vice President for Policy at Cure SMA, at [maynard.friesz@curesma.org](mailto:maynard.friesz@curesma.org) or 202-871-8004, should they have questions or need additional information.

Sincerely,

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

Kenneth Hobby  
President  
Cure SMA

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

Maynard Friesz  
Vice President of Policy & Advocacy  
Cure SMA