



Make today a breakthrough.

May 8, 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 you prepare to reauthorize the Pandemic and All-Hazards Preparedness Act (PAHPA), **Cure SMA respectfully asks that you prioritize emergency and pandemic preparedness and response for people with spinal muscular atrophy (SMA) and other disabilities.** As the Administration for Strategic Preparedness and Response official [noted](#) at last week's U.S. Senate Health, Education, Labor, and Pensions (HELP) Committee PAHPA hearing, our country *"is not prepared until we are all prepared, all communities—those at greatest risk need to be accounted for in all the planning we do and the response we do."*

**Unfortunately, individuals with SMA fear (even expect) an inadequate government emergency response for people with disabilities.** Many individuals with SMA, a neuromuscular disease, utilize a power wheelchair for their mobility and require in-home assistance with their activities of daily living. These supports are especially essential during an emergency. However, individuals with SMA cannot rely on the government's response to ensure their needs will be met in a future pandemic, natural disaster, or other emergency. During a past hurricane evacuation, a **woman with SMA** who uses a power wheelchair had to send out her own social media pleas for assistance to safely evacuate from her flooded home due to her community's limited emergency response. Less severe storms can also cause significant challenges for people with SMA. A **man with SMA** described how power outages impact his ability to operate his electricity-dependent suction machine, nebulizer, and ventilator. Other **individuals with SMA** worry they will lose their in-home care and support which they need for daily activities if they are evacuated to another community. Accessing personal care attendants was especially problematic for children and adults with SMA and their families during the COVID-19 pandemic.



Cure SMA and the SMA community view the upcoming PAHPA reauthorization as an opportunity to address the concerns and challenges of people with SMA and other disabilities. To ensure our country achieves the *“not prepared until we are all prepared”* standard highlighted at last week’s HELP Committee hearing, we ask that you consider the following in the next PAHPA to ensure the needs of people with SMA and other disabilities are accounted for and met:

- prohibit discrimination of emergency care and treatment based on disability,
- ensure states and local jurisdictions include people with disabilities in their emergency preparedness and response plans, and
- provide immediate local support and assistance to people with disabilities impacted by an emergency.

Cure SMA supports disaster provisions included in the recently introduced Real Emergency Access for Aging and Disability Inclusion for Disasters Act (S. 1049). However, we would support other related provisions that ensure that state and local officials develop strategies that reflect the feedback of people with disabilities and that state and local governments can access resources to address the needs of people with disabilities in times of emergency. *“It’s very scary to have a disability and then have more issues to try to figure out,”* an **adult with SMA** said related to the likelihood of another pandemic or major emergency. Cure SMA asks that you keep the views and concerns of people with SMA in mind as you develop the next Pandemic and All-Hazards Preparedness Act.

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