



Make today a breakthrough.

August 9, 2021

The Honorable Bob Casey  
The Honorable Richard Blumenthal  
The Honorable Sherrod Brown  
The Honorable Chris Van Hollen  
The Honorable Elizabeth Warren  
United States Senate  
Washington, DC 20510

The Honorable Jimmy Panetta  
The Honorable James R. Langevin  
The Honorable Jenniffer Gonzalez  
United States House of Representatives  
Washington, DC 20515

Dear Senators and Representatives:

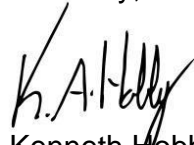
As the leading national organization that represents individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), **Cure SMA is pleased to support the Disaster Relief Medicaid Act, legislation you sponsored to ensure emergency disaster planning and response are effective and inclusive for people with SMA and other disabilities.**

SMA is a degenerative disease that robs individuals of physical strength, greatly impacting their ability to walk, eat, and perform other essential functions of everyday life. Natural disasters or other emergencies, especially those that result in mandatory evacuations, can pose significant challenges for people with SMA. For example, a young woman with SMA who utilizes a power wheelchair had to send out her own social media pleas for assistance to seek help from friends to safely evacuate from her flooding home during a past hurricane. In addition, individuals with SMA who rely on personal care attendant (PCA) services provided through Medicaid risk losing their essential supports if they are forced to evacuate across state lines due to an emergency.

**The Disaster Relief Medicaid Act (S. 2646)** would help ensure individuals with disabilities, including those with SMA, who are eligible for Medicaid services, such as PCAs, can still access their Medicaid-funded home and community-based services if they need to relocate due to a disaster. Under the legislation, states would receive a temporary 100 percent federal match for Medicaid services and assistance provided to relief-eligible survivors of a major disaster. This provision will provide continuity of services to Medicaid-eligible individuals with disabilities who relocate to another state due to an emergency evacuation. **Cure SMA strongly supports the Disaster Relief Medicaid Act and urges the 117th Congress to quickly approve this legislation.**

Thank you for your leadership and support in ensuring our nation's emergency disaster planning and response meets the needs of people with SMA and other disabilities. For more information, your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at [maynard.friesz@curesma.org](mailto:maynard.friesz@curesma.org) or 202-871-8004.

Sincerely,

  
Kenneth Hobby  
President

  
Maynard Friesz  
Vice President of Policy & Advocacy