



Make today a breakthrough.

August 9, 2021

The Honorable Bob Casey
The Honorable Richard Blumenthal
The Honorable Tammy Duckworth
The Honorable Amy Klobuchar
The Honorable Kirsten Gillibrand
The Honorable Chris Van Hollen
The Honorable Elizabeth Warren
United States Senate
Washington, DC 20510

The Honorable James R. Langevin
The Honorable Christopher H. Smith
The Honorable Jimmy Panetta
The Honorable Albio Sires
The Honorable Eleanor Holmes Norton
The Honorable Derek Kilmer
The Honorable Brian K. Fitzpatrick
The Honorable Jamaal Bowman
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 Real Emergency Access for Aging and Disability Inclusion (READI) for Disasters Act, legislation you sponsored to help 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 Real Emergency Access for Aging and Disability Inclusion (READI) for Disasters Act (S. 2658/ H.R. 4938) would improve emergency disaster planning and response for people with disabilities. The legislation would, among other things, establish a National Commission on Disability Rights and Disasters to study the emergency preparedness and response needs of individuals with disabilities, create a network of technical assistance and training centers to assist states and localities in meeting the emergency disaster needs of people with disabilities, and create a competitive grant program to pilot strategies involving and meeting the needs of people with disabilities in disaster preparation, response, recovery, and mitigation.



Cure SMA strongly supports the READI for Disaster Act (S. 2658/ H.R. 4938) and urges the 117th Congress to quickly approve the 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 at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004.

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