



Make today a breakthrough.

May 14, 2024

The Honorable Marc Molinaro
U.S. House of Representatives
1207 Longworth Bldg.
Washington, DC 20515

The Honorable Mikie Sherrill
U.S. House of Representatives
1427 Longworth Bldg.
Washington, DC 20515

Dear Representatives Molinaro and Sherrill:

As the leading national organization that represents individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), **Cure SMA appreciates your efforts to increase consumer-friendly information about caregiving and other federal, state, and local services and programs available to people with disabilities.** We are especially appreciative of your interest in expanding the definition of disability in your bipartisan Think Differently Database Act (H.R. 670) to also include individuals with physical disabilities, such as SMA.

SMA is a degenerative disease that robs individuals of physical strength, greatly impacting their ability to walk, move and lift their arms, and perform other essential functions of everyday life. Individuals with SMA benefit from Medicaid-funded home and community-based services (HCBS), such as home health, respite care, and rehabilitative services, to promote independence and assist with activities of daily living. For example, a personal care attendant (PCA) may assist an individual with SMA in getting out of bed and dressed in the morning so they can get to work or attend school.

Unfortunately, individuals with SMA face multiple barriers in accessing caregivers and caregiving services, even in understanding what caregiving options are available to them in their states. Cure SMA learned that [47 percent](#) of individuals with SMA and their families struggled to find information about paid caregiving options in their state. A Cure SMA review of state Medicaid webpages found state caregiving information “hard-to-find, confusing, inconsistent, and not consumer-oriented.” A **woman with SMA** said, “*I couldn’t find information directly online about the waiver program that I use. I only found out about it through my counselor at the Division of Rehabilitative Services.*” In our recent [Stuck Inside National Caregiving Report](#), Cure SMA recommended that states be required to make online information about their Medicaid waiver program and related caregiving services available in an interactive, consumer-friendly, plain language online web page or portal.

Expanding the disability definition within your Think Differently Database Act would help ensure that all individuals with disabilities, including those with SMA, are aware of the federal, state, and local caregiving and other services that exist that can help them maintain their health and independence. **Cure SMA strongly supports your legislation’s goal of creating an interactive, searchable webpage that provides a comprehensive clearinghouse of information, services, and programs available to individuals with disabilities and their families. By expanding the definition of disability in your legislation to include all**



individuals with disabilities, including those with physical disabilities, the proposed online resource will have even greater use and impact.

Cure SMA is grateful for your leadership in helping to increase awareness about and breaking down barriers to caregiving and other services and programs available to individuals with SMA and other disabilities. We look forward to working with you and your staff to adopt your Think Differently Database Act, with the expanded disability definition, and to secure final passage in Congress before the end of the year. If you have questions or need additional information, your staff can reach out to Maynard Friesz, Cure SMA Vice President of Policy and Advocacy, at maynard.friesz@curesma.org or 202-871-8004.

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