



Make today a breakthrough.

April 5, 2024

The Honorable Ayanna Pressley of Massachusetts
The Honorable Pramila Jayapal of Washington
The Honorable Barbara Lee of California
The Honorable Stephen F. Lynch of Massachusetts
The Honorable James P. McGovern of Massachusetts
The Honorable Seth Moulton of Massachusetts
The Honorable Eleanor Holmes Norton of the District of Columbia
The Honorable Alexandria Ocasio-Cortez of New York
The Honorable Delia C. Ramirez of Illinois
The Honorable Jan Schakowsky of Illinois
The Honorable Rashida Tlaib of Michigan
The Honorable Paul Tonko of New York

Dear Members of Congress:

On behalf of children and adults with spinal muscular atrophy (SMA) across the country, **Cure SMA applauds your efforts to ensure that individuals with SMA and other disabilities can access medical examination tables, weight scales, and other medical diagnostic equipment (MDE).** Cure SMA appreciates your recent letterⁱ to the U.S. Department of Justice (DOJ) in support of its proposal to require accessible MDE at hospitals and health clinics operated by state or local governments.

SMA is a neuromuscular disease that impacts the muscles used for everyday living activities such as walking, eating, and breathing. Due to muscle loss associated with SMA, many individuals with SMA struggle to access the healthcare they need because of inaccessible MDE and other physical barriers. *"I don't even bother transferring into any exam tables because it's hard to transfer and, without back or arm support, they are not supportive enough for me to use,"* said an **adult woman with SMA**. Another **adult with SMA** has gone years without an accurate weight check. *"A lot of my doctors' offices don't have an accessible scale for wheelchairs and so at most of these places I just get an estimate."* An inaccurate weight estimate is especially problematic for those individuals with SMA whose medication dosage is determined by weight. *"I may not be receiving the full benefit of these medications that are so dependent on my weight."*

Cure SMA agrees with you that DOJ's proposal is "long overdue" and if implemented would "result in more timely and accessible care for the disability community," as you wrote in your April 2, 2024 letter. In our own comment letter to DOJ, Cure SMA shared numerous examples of how inaccessible MDE has significantly limited or delayed access to healthcare services for people with SMA.ⁱⁱ *"For far too long, the burden has been exclusively placed on individuals with disabilities,"* we shared with DOJ. *"Cure SMA supports the immediate implementation of this proposal and hopes that it leads to improved accessibility for individuals with SMA and other disabilities at all physicians' offices, clinics, emergency rooms, hospitals, and other settings."*



Access to healthcare is a top priority for the SMA community. We are grateful for your leadership and support for this accessible MDE proposal, which represents a meaningful step forward in improving access to healthcare services. Your staff can reach out to Cure SMA at maynard.friesz@curesma.org or 202-871-8004 should they have questions.

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 & Advocacy

ⁱ Members of Congress write to DOJ in Support of Accessible MDE, 2024, <https://pressley.house.gov/wp-content/uploads/2024/04/2024-04-03-Letter-to-DOJ-on-Improving-Healthcare-Access-for-Disability-Community.pdf>

ⁱⁱ Cure SMA Comment Letter on DOJ Accessible MDE Proposal, 2024, <https://www.curesma.org/wp-content/uploads/2024/02/Cure-SMA-Comments-on-Accessible-Medical-Diagnostic-Equipment.pdf>