Make today a breakthrough.

February 7, 2024

The Honorable Rebecca Bond
Chief, Disability Rights Section
Civil Rights Division
200 Independence Avenue, SW
Washington, DC 20201

Re: Comments on DOJ Enforcement of Accessible Medical Diagnostic Equipment

Dear Chief Bond:

As the leading national organization that represents individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), Cure SMA appreciates the opportunity to comment on the U.S. Department of Justice (DOJ) proposal to ensure that individuals with SMA and other disabilities can access medical examination tables, weight scales, and other medical diagnostic equipment (MDE) at hospitals and health clinics operated by state or local governments.

SMA is a genetic disease caused by a mutation in the survival motor neuron gene 1, or SMN1. In a healthy person, this gene produces a protein that is critical to the function of the nerves that control our muscles. Without it, those nerve cells die, impacting an individual's ability to crawl, walk, eat, and breathe. SMA impacts 1 in 11,000 births in the United States and 1 in 50 Americans is a SMA carrier. If both parents are SMA carriers, every child they have together has a 25% chance of being diagnosed with SMA, regardless of race, ethnicity, and gender.

While annual hospitalizations have decreased since the advent of SMA treatments[i], individuals with SMA still have higher rates of healthcare utilization than individuals without SMA.[ii] Individuals with SMA regularly interact with the healthcare system for routine checkups, to receive an SMA treatment, or to access specialized care for respiratory, orthopedic, or other chronic challenges associated with the disease. One **parent of a child with SMA** said she spent *"countless days and scores of hours"* managing doctor's visits, medical appointments, and other healthcare needs for her child with SMA.[iii]

Cure SMA applauds DOJ for its effort to reduce barriers and promote equal access to quality healthcare for people with disabilities, including those living with SMA.[iv] Many individuals with SMA face inaccessible MDE and other physical barriers that significantly limit or delay their access to healthcare services. An **adult with SMA** shared how she walked out of a clinic for a routine x-ray exam after being assured they were set up to accommodate her power wheelchair. *"Sometimes, the clinic's set-up just doesn't work. And I have to go to different clinics until I can find one that does work,"* she said. A **woman with SMA** described how she has had to reschedule or experienced long waits *"until they figure out how to better accommodate me."*

Cure SMA supports the proposal to make the U.S. Access Board's MDE accessible standards enforceable under Title II of the Americans with Disabilities Act (ADA).[v] If implemented, health clinics and hospitals operated by state and local governments would be required to make available accessible exam tables, scales, x-ray machines, and other MDE so that all patients have equal access to health services and medical tests. DOJ pointed to numerous complaints and examples of individuals with disabilities who faced discrimination or have foregone basic care due to inaccessible DME.[vi] This is a common experience across the SMA community. *"I have gone multiple years without ever getting my weight done because my doctor's office can never do it,"* said a **young adult with SMA** who utilizes a power wheelchair. Another **adult with SMA** from a different part of the country shared a similar experience. "*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."*

Throughout the proposal, DOJ seeks public comment to determine the burden the MDE proposal may have on public entities. For far too long, the burden has been exclusively placed on individuals with disabilities. *"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 a **person with SMA**. The provisions within the DOJ proposal would promote better and equal care by requiring a certain percentage of MDE at government-operated clinics and hospitals are accessible. Cure SMA believes the 10 percent, but not less than one unit requirement for regular clinics and physician's offices and the higher 20 percent threshold for facilities that specialize in treating mobility-related conditions are meaningful and workable. The proposal also requires public entities that provide health care to provide reasonable assistance, such as wheelchair-to-MDE transfers, to comply with the equal access requirement. *"Unless there is a nurse to help out, there is no real way to safely transfer onto the exam table,"* said a **woman with SMA**. These requirements are more than reasonable, especially given the rule provides an exception if compliance would result in an undue financial or administrative burden or would fundamentally alter the nature of the service or program.[vii]

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 medical settings. Thank you for your considering the views and comments of the SMA community. For more information, please contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004.

Sincerely,

K.A.Hobby

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President
Cure SMA

Maynard Friesz

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[i] 2022 State of SMA Report, Cure SMA, https://www.curesma.org/wp-content/uploads/2023/06/9062023_State-of-SMA_vWeb.pdf

[ii] Economic Burden of Spinal Muscular Atrophy, Journal of Market Access & Health Policy, 2020 https://www.tandfonline.com/doi/pdf/10.1080/20016689.2020.1843277?needAccess=true

[iii] Voice of the Patient, Cure SMA, 2017, https://www.curesma.org/wp-content/uploads/2018/01/SMA-VoP-for-publication-1-22-2018.pdf

[iv] Accessibility of Medical Diagnostic Equipment Fact Sheet, DOJ, 2024, https://www.ada.gov/notices/2024/01/10/mde-nprm/

[v] Accessibility of Medical Diagnostic Equipment Fact Sheet, DOJ, 2024, https://www.ada.gov/notices/2024/01/10/mde-nprm/

[vi] DOJ DME Rule, Federal Register, 2024, https://www.govinfo.gov/content/pkg/FR-2024-01-12/pdf/2024-00553.pdf

[vii] Section 35.211(e), DOJ DME Rule, Federal Register, 2024, https://www.govinfo.gov/content/pkg/FR-2024-01-12/pdf/2024-00553.pdf