



Make today a breakthrough.

May 7, 2024

Re: Please Sign onto HUD Section 811 Funding Dear Colleague (Menendez)

Dear Member of Congress,

On behalf of individuals and families impacted by spinal muscular atrophy (SMA), **Cure SMA respectfully asks that you sign onto the Dear Colleague letter to Senators Schatz and Hyde-Smith in support of fiscal year 2025 funding for Section 811 programs for persons with SMA and other disabilities.** The Section 811 program at the U.S. Department of Housing and Urban Development (HUD) is critical to housing many individuals with SMA who need affordable accessible housing to access the community around them.

SMA is a rare degenerative neuromuscular disease that robs individuals of their physical strength, greatly impacting their ability to walk, sit without support, transfer independently, and perform other essential functions of everyday life. Daily living tasks, including getting out of bed, bathing, cooking, and toileting, require adaptations or assistance. An individual's ability to perform these tasks often depends on the accessibility of their home environment.

Rental programs under Section 811 provide accessible housing assistance for those with low incomes, including many of the [19 percent of families and individuals with SMA](#) who reported a yearly household income under \$20,000. This population of low income SMA families, is extremely vulnerable as they require both housing that is affordable and accessible, as most depend on large power wheelchairs for their mobility. The search for accessible housing often leaves many individuals with SMA and their families feeling helpless. "My niece and her son were in the shelter system because it was difficult to secure a wheelchair accessible apartment," said a SMA family member.

A lack of affordable accessible housing forced an adult with SMA from Rochester, NY into an extended institutionalization situation when he was 15. "I was told I would only have to be there for a month, I ended up living there for 5 years, 10 months, and 5 days." After years of waiting, he finally secured Section 811 housing. However, his apartment had significant barriers, including a bathroom that was too small to accommodate his power wheelchair and that lacked an accessible shower.

The Dear Colleague letter would support FY 2025 funding to renew and expand housing for people with disabilities and make common-sense improvements, to ensure funds can be used for modifications and tenant caused damages, that are common for tenants who use wheelchairs, and in their homes. In addition, the included recommendation would make two-person households with two SSI recipients with a combined income is over 30% of AMI under 50% of AMI, eligible for the 811 PRA program. This would allow many individuals with SMA who live with a family member, friend, or caregivers also on SSI to be eligible for this affordable accessible housing program.



Please consider signing onto Senator Menendez's Dear Colleague letter in support of HUD's Section 202 and 811 programs by contacting Jonathan Tsentas (jonathan_tsentas@menendez.senate.gov). **The deadline to sign the letter is May 9.**

Please don't hesitate to contact Cure SMA should you have any questions or need further information, your staff contact Sarah Bellish, Manager of Policy and Advocacy at Cure SMA, at 202-871-8005 or sarah.bellish@curesma.org.

Sincerely,

A handwritten signature in black ink that reads "K. A. Hobby".

Kenneth Hobby

President, Cure SMA