



September 22, 2025

The Honorable Rick W. Allen
United States House of Representatives
Washington, DC 20515

The Honorable Lucy McBath
United States House of Representatives
Washington, DC 20515

The Honorable Mariannette Miller-Meeks
United States House of Representatives
Washington, DC 20515

The Honorable Raul Ruiz
United States House of Representatives
Washington, DC 20515

The Honorable Bob Onder
United States House of Representatives
Washington, DC 20515

Dear Representatives Allen, McBath, Miller-Meeks, Ruiz, and Onder,

On behalf of individuals and families impacted by spinal muscular atrophy (SMA), **Cure SMA thanks you for reintroducing the Safe Step Act.** Your bipartisan legislation underscores the importance of patient choice and timely access to life-saving treatments for people with SMA and other chronic conditions.

SMA is a debilitating neuromuscular disease that causes irreversible nerve damage and severe muscle loss, impairing a person's ability to walk, breathe, and perform daily activities. The disease affects both children and adults in all 50 states.

Today, multiple FDA-approved SMA treatments are extending survivability and significantly improving health and quality of life for individuals with SMA. Since these therapies became available, the SMA mortality rate has dropped by 80 percent. Hospitalizations and reliance on intensive, costly medical equipment and health services, such as respiratory supports, have also decreased.ⁱ **One teenager with SMA** shared, *"Before I started treatment I was often hospitalized for many reasons. Since starting treatment, I have not been unexpectedly hospitalized."* These improved health outcomes are possible because of early diagnosis through nationwide newborn screening and access to SMA treatments based on each individual's clinical needs.

Unfortunately, this progress can be threatened by restrictive insurance policies and harmful utilization protocols such as step therapy. Step therapy requires patients to first try a health plan's preferred treatment, even when their physician has already prescribed a more appropriate therapy. As one **adult with SMA** said, *"It's exhausting physically and mentally trying to navigate such an important treatment with insurance companies that don't understand and just want to check boxes and never really take time to understand."*

Most individuals with SMA report experiencing insurance delays or denials for their prescribed SMA treatment.ⁱⁱ Given the rapid and irreversible loss of motor neurons, muscles, and motor function, any delay in accessing the treatment chosen by the patient and prescribed by their doctor can cause lasting harm and lead to more costly healthcare interventions. An **older adult with SMA** noted that a past insurance delay caused *"great stress and continued loss of*

*strength.” Another **adult with SMA** said, “The longer the delay, the more my condition progresses.”*

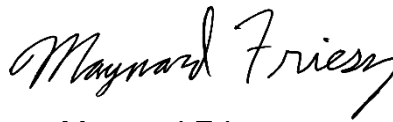
The Safe Step Act would help protect patient choice and promote access to effective treatments by requiring insurance plans to adopt a clear, transparent, and expedited process for patients or physicians to request exceptions to step therapy protocols. This legislation will ensure that individuals with SMA can access the treatments that best meet their unique clinical needs, based on their healthcare provider’s expert judgment.

Cure SMA and the SMA community thank you for supporting the healthcare needs of children and adults with SMA. We look forward to working with you and your staff to advance this important legislation in the 119th Congress. If you have questions, your staff can reach out to Cure SMA through Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at 202-871-8004 or maynard.friesz@curesma.org.

Sincerely,



Kenneth Hobby
President



Maynard Friesz
Vice President of Policy

ⁱ Cure SMA State of SMA Report, 2025, https://www.curesma.org/wp-content/uploads/2025/04/State-of-SMA-Report2024_vWeb.pdf#page=40

ⁱⁱ Cure SMA State of SMA Report, 2025, https://www.curesma.org/wp-content/uploads/2025/04/State-of-SMA-Report2024_vWeb.pdf#page=30