



March 10, 2025

The Honorable Steve Cohen United States House of Representatives 2268 Rayburn House Office Building Washington DC 20515

Dear Representative Cohen

As the leading national organization that represents individuals with spinal muscular atrophy (SMA), a neuromuscular disease, Cure SMA is pleased to support your Mobility Means Freedom Tax Credit Act. Your legislation would help promote access to mobility devices that individuals with SMA and others require for their health, independence, and community living.

SMA is a genetic neurodegenerative disease that attacks the nervous system and robs individuals of physical strength, taking away their ability to walk, sit without support, and perform other essential functions of everyday life. Approximately 1 in 50 people is a genetic carrier for SMA, including more than 138,000 residents of **Tennessee**. If both parents are SMA carriers, every child they have together has a 25% chance of being diagnosed with SMA.

Due to debilitating muscle weakness associated with SMA, more than 80% of children and adults with SMA regularly utilize durable medical equipment (DME), including power wheelchairs, manual wheelchairs, and other mobility devices. Most individuals with SMA who use a wheelchair spend at least 7 hours daily in their chairs, including 47% who use a wheelchair "more than 12 hours per day," according to a Cure SMA survey. "Wheelchairs are our legs. Wheelchairs are a lifeline. Wheelchairs are independence," said an adult with SMA.

In addition, the wheelchairs used by individuals with SMA are often specially tailored to meet their individual needs. For example, a person who is unable to sit independently due to SMArelated muscle weakness may require a customized seat and cushions to provide greater trunk control and breathing support. Other individuals with SMA require enhanced options such as seat elevation or standing systems to reduce pain, promote health, and increase independence. Specialized power wheelchairs commonly used by individuals with SMA can cost several thousand dollars. A recent Cure SMA report found that 25 percent of individuals who utilize DME, such as wheelchairs, were denied by their insurance, forcing them to go without or find other means to purchase.

The Mobility Means Freedom Tax Credit Act recognizes the essential nature of wheelchairs and other mobility devices by providing individuals with SMA and others with a tax credit to offset costs associated with purchasing or repairing a mobility device. Cure SMA appreciates that your legislation recognizes the wide range of mobility devices that individuals with SMA and other disabilities use and need, including wheelchairs, scooters, leg braces, and device enhancements.



Cure SMA strongly supports the Mobility Means Freedom Tax Credit Act. We look forward to working with you to advance this important legislation in the 119th Congress. For more information, your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at 202-871-8004 or maynard.friesz@curesma.org.

Sincerely,

Kenneth Hobby

President

Mayord Friesz

Vice President of Policy & Advocacy