September 8, 2026

The Honorable Maxwell Frost
United States House of Representatives
Washington DC 20515

Dear Representative Frost:

As the leading national organization that represents individuals with spinal muscular atrophy (SMA), a neuromuscular disease, **Cure SMA is pleased to support your Wheelchair Right to Repair Act (H.R. 5039)**. Your legislation would help ensure that individuals with SMA and others who rely on power wheelchairs can get their equipment repaired quickly, affordably, and without unnecessary barriers.

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. Nearly 80% of children and adults with SMA regularly utilize power wheelchairs and other durable medical equipment (DME).[i] As one **adult with SMA** put it, "*Wheelchairs are our legs. Wheelchairs are a lifeline. Wheelchairs are independence.*"

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 SMA-related muscle weakness may require a customized seat and cushions to provide greater trunk control and breathing support. Others rely on seat elevation and standing systems on their power wheelchairs to reduce pain, promote health, and increase independence. People with SMA who use a power wheelchair report spending 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.

Unfortunately, many individuals with SMA face significant delays and other obstacles when their wheelchairs break down or need repairs. Wheelchair users are often required by manufacturers, insurance policies, or warranty agreements to use designated or manufacturer-authorized repair providers, limiting their ability to seek faster or more local repair options. A **mother of two elementary school-aged children with SMA** said a DME provider showed no urgency to repair one of her boys' power wheelchairs. *"There was no clear timeline for when the chair would be operable again and no offer of an appropriate replacement or loaner."*

It took two weeks for an **adult with SMA** to get a flat tire replaced on her wheelchair and she considered herself fortunate, noting that others faced longer delays for the same kind of repair. *"If I were dealing with a flat tire on my car rather than my wheelchair, my experience would be completely different. I would have several immediate options: I could go to a local tire shop, purchase a replacement, or order one online. But repairing a wheelchair is not as consumer-friendly in the same way."* Scheduling backlogs, parts shortages, poor customer service, and a lack of urgency are common among other wheelchair users, according to a national report.[ii]

The Wheelchair Right to Repair Act recognizes the significant challenges and lengthy delays individuals with SMA and others who use power wheelchairs face in getting their

wheelchairs repaired. Your legislation would require manufacturers of powered mobility devices to make parts, embedded software, firmware, tools, and documentation available to consumers and independent repair providers on fair and reasonable terms, and would create a copyright exception so that diagnosing, maintaining, and repairing a wheelchair is not treated as a violation of federal law. Your legislation would help empower wheelchair users by allowing them to seek faster, more affordable repairs rather than being limited to a single manufacturer-authorized provider.

Cure SMA supports the Wheelchair Right to Repair Act as one way to help address the wheelchair repair challenges faced by people with SMA. Cure SMA looks 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

Maynard Friesz
Vice President, Policy

[i] State of SMA Report, Cure SMA, 2026, https://www.curesma.org/wp-content/uploads/2026/05/2025_State-of_SMA_Report_vWeb.pdf#page=31

[ii] Stranded Report, U.S. PIRG Education Fund, https://publicinterestnetwork.org/wp-content/uploads/2022/05/USPIRGEF_Stranded_June2022.pdf