



April 30, 2025

The Honorable Representative Susan Donovan, Chair
House Health and Human Services Committee

Re: Support for H.6209– Related to Insurance – Prescription Drug Benefits

Dear Chair Donovan and members of the Committee,

My name is Danielle Spadafora and I am the Managing Director of Advocacy for the ALS Association. On behalf of the ALS Association and the patients we serve in Rhode Island, I would like to express our strong support for H.6209, which will significantly help reduce the out-of-pocket healthcare costs for our community.

Amyotrophic lateral sclerosis (ALS) or “Lou Gehrig’s” is a fatal progressive neurodegenerative disease that slowly robs a person’s ability to walk, talk, eat, and eventually breathe. The cost of care for someone living with ALS is astronomical, with annual out-of-pocket expenses reaching as much as \$250,000 per year. The disease forces patients to leave the workforce, and often times their spouses become the primary caregivers, forcing them to stop working as well. As with many people living with complex medical conditions, those with ALS must take various drugs to maintain their health. The copays associated with acquiring them significantly add to this crushing financial burden.

One way that patients afford their care is through copay assistance programs, where cards or coupons from nonprofit organizations or drug manufacturers help reduce the cost of drugs. However, insurers and pharmacy benefit managers increasingly use **copay accumulator adjustment programs** to prevent such assistance from counting towards patient cost-sharing, such as their deductible or annual out-of-pocket maximum. In effect, the insurer gets to “double-dip” by demanding payment of out-of-pocket costs: first from copay assistance programs and then again from patients.

Copay accumulator adjustment programs do not just harm patients’ wallets; they undermine their access to life-saving prescription drugs, making it even more difficult for people living with ALS and other complex medical conditions to adhere to a treatment plan. With lower copays, consumers are less likely to skip taking their medication, which for ALS patients, extends the very little time they have left.

ALS is an always-fatal disease; there is no cure, and an average person with ALS lives between 2-5 years. Affording and adhering to their medication helps to extend their lives and the time they can spend with their loved ones. Imagine someone with this devastating diagnosis deciding to skip their medication simply because they could not afford the copayment, knowing that that the insurer is effectively paid twice.

As one of the leading patient advocacy organizations in the nation, The ALS Association supports the prohibition of copay accumulator adjustment programs. We believe that all patients should be able to afford necessary treatments by ensuring all payments – made by or on behalf of the patients – are counted towards a patients’ deductible and out-of-pocket maximums.

Thank you for your time and your consideration of this critical legislation. For all these reasons, I respectfully ask for your support on H.6209.

Sincerely,

Danielle Spadafora, MPH
Managing Director, Advocacy
ALS Association