



March 28, 2024

The Honorable Virginia Lyons  
Chair, Senate Committee on Health and Welfare  
115 State Street Montpelier, VT 05633

**Re: Support for H.766 - An act relating to prior authorization and step therapy requirements, health insurance claims, provider contracts, and collection of cost sharing amounts**

Dear Chair Lyons, Vice Chair Weeks, and members of the Senate Committee on Health and Welfare,

On behalf of The ALS Association and the roughly 50 families we serve in Vermont, we urge you to swiftly move H.766 through your committee. This legislation addresses three issues that significantly impact people living with ALS and other diseases: prior authorization, step-therapy protocols, and copay accumulator adjustment programs.

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, usually within 2-5 years of diagnosis. It is a devastating condition that can strike anyone at any time and currently has no known cures. Given the severity and rapid progression of ALS, timely access to necessary medical interventions, treatments, and support services are paramount, as well as ensuring that treatments are affordable to patients.

Currently, the prior authorization process poses significant obstacles and delays for ALS patients, impeding their access to critical treatments and therapies. According to the AMA, 91% of physicians said that prior authorization requirements had a somewhat or significant negative impact on patients’ clinical outcomes. In addition, the cumbersome nature of prior authorization requirements not only undermines the quality of care but also exacerbates the physical, emotional, and financial burdens faced by people living with ALS and their families. Implementing reform in prior authorization practices would alleviate these burdens and enhance the quality of life for people living with ALS.

Another issue that currently hinders people living with ALS from accessing the treatments they need are step-therapy protocols. When an insurer requires a patient to “fail” on a medication before moving onto another, they are wasting precious time and potentially preventing them from life-extension or a slowed prognosis that they may receive with another treatment. When new treatments are approved, it is common for a specialist to recommend trying a new medication or a combination of several, in the hope that the patient may have a more successful outcome. In the recommended treatment is not covered by the insurer or is more expensive, they can be denied access to the treatment, or expected to spend several months using a medication that has not worked for them and is not their recommended treatment. People living with ALS should have barrier-free access to the medications as prescribed by their providers.

ALS is currently an incurable disease. The drugs currently approved for treatment of ALS extend life by a matter of months and help to improve the quality of life that the patient has left. With ALS patients only living between 2-5 years, they do not have the time to wait around through prior authorizations and step-therapy protocols, and when new drugs are approved for the treatment of this always-fatal disease, they should be easier to access if they are prescribed by a doctor specializing in the treatment of ALS.



In addition to these burdensome processes that prevent people living with ALS from accessing the care they need, the cost of care for someone living with ALS is astronomical, with annual out-of-pocket expenses reaching upwards of \$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, are extending the very little time they have left. 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 the insurer is effectively paid twice. The ALS Association believes 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.

In conclusion, I implore the Seante Committee on Health and Welfare to recognize the pressing need for prior authorization reform, to do away with limiting step-therapy protocols, and to ensure that patients can afford their prescriptions by ensuring that all copays count toward their cost-sharing. By implementing more efficient and patient-centered processes, you can positively impact the lives of countless individuals living with this devastating disease and other conditions.

Thank you for your attention and anticipated support on these issues, and I urge you to vote H.766 favorably out of your committee. I remain hopeful that together, we can make a tangible difference in the lives of those affected by ALS.

Sincerely,

**Danielle Adams, MPH**  
Managing Director, Advocacy (Northeast)  
The ALS Association  
Danielle.adams@als.org