



April 1, 2025

The Honorable Representative Susan Donovan, Chair
House Health and Human Services Committee
State of Rhode Island General Assembly

Re: Support for H5119 Relating to Insurance – Benefit Determination and Utilization Review Act

Dear Chair Donovan and Members of the Committee,

I am writing on behalf of The ALS Association and the patients and their families in the State of Rhode Island, in support of S5119. We are grateful for your sponsorship of this critical legislation, which would remove step therapy requirements that negatively impact people living with ALS and other diseases.

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.

Step-therapy protocols currently hinder people living with ALS from accessing the treatments they need. 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 for ALS, 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 ineffective 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.

The RI legislature must recognize the pressing need to do away with harmful and limiting step-therapy protocols. By implementing more efficient and patient-centered processes, the state can positively impact the lives of individuals living with this devastating disease and other conditions. For all these reasons, we strongly support H5119 and encourage you to move this favorably through committee.

Sincerely,
Danielle Spadafora
Managing Director, Advocacy
The ALS Association