



March 18, 2024

The Honorable Susan Donovan, Chair  
House Health & Human Services Committee  
82 Smith St, Providence, RI 02903

**Re: Support for H.7822 – Relating to Insurance – Benefit Determination and Utilization Review Act**

Dear Chair Donovan and members of the House Health and Human Services Committee,

On behalf of The ALS Association and the people we serve in Rhode Island, we strongly support H.7822, 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.

H.7822 would create step therapy exception and permit immediate coverage if the step it required has been tried and is ineffective, is expected to be ineffective, is expected to cause an adverse reaction, or will delay or prevent necessary care for the patient. 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.

In conclusion, I implore the House Health and Human Services Committee to recognize the pressing need to do away with harmful and limiting step-therapy protocols. 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.782 favorably out of your committee.

Sincerely,

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The ALS Association  
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