

Ernesta P Kennedy
Windham
LD 1577

May 9, 2023

The Honorable Senator Donna Bailey
The Honorable Representative Anne Perry
Committee on Health Coverage, Insurance and Financial Services

RE: Support for L.D.1577 An Act to Require Health Insurance Coverage for Biomarker Testing

Dear Chairs Bailey and Perry and Members of the Committee,

I am writing today as a person who lost their husband and father of our three boys to amyotrophic lateral sclerosis (ALS) or “Lou Gehrig’s” to ask that you support L.D.1577 An Act to Require Health Insurance Coverage for Biomarker Testing. This legislation would increase access to biomarker testing for more Mainers living with ALS and other diseases.

Biomarker testing is an essential step to accessing precision medicine that can lead to improved survivorship and better quality of life for patients. A biomarker is a molecular signature, like a protein or gene, that can provide insights into medical conditions or diseases like ALS, cancer, arthritis, mental health, and more. The results of a biomarker test give providers knowledge that can guide a patient's treatment plan, potentially providing access to targeted treatment that can improve disease outcomes, quality of life for patients, and reduce costs. In some cases, paying upfront for comprehensive testing can result in overall savings in treatment costs.

However, insurance coverage is failing to keep pace with innovations and advancements in treatment for serious diseases and conditions. When biomarker testing is not covered by insurance, patients can be on the hook for hundreds or even thousands of dollars in out-of-pocket costs. This bill would require state-regulated health insurance plans to cover comprehensive biomarker testing when supported by medical and scientific evidence. While biomarkers are primarily used in oncology, more are being discovered every day and are in the research pipeline for chronic and rare diseases, like ALS.

ALS is an always-fatal neurodegenerative disease in which a person’s brain loses connection with their muscles. As a result, people with ALS lose their ability to walk, talk, eat, and eventually breathe. There is no cure, but there are a few drugs on the market that have been shown to slow the progression of the disease. When people living with ALS are already losing so much of their bodies, they should not have to worry about losing access to the extra time with their loved ones and the benefits that these tests provide.

Thank you for your time and your consideration of this critical legislation. For all these reasons, I respectfully ask for your support on L.D.1577.

Sincerely,
Ernesta P. Kennedy
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