

May 5, 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 someone personally impacted by 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. As a neuroscience PhD student and researcher, I can stress the importance of using biomarker testing to its full capacity and how it beneficially impacts patients’ treatment opportunities. I do not speak on behalf of the institution I am receiving my degree from, Tufts University, or where I conduct my research, the Jackson Laboratory, but rather on behalf of myself using my personal experience, opinions, and thoughts. As a neuroscience graduate student specializing in neurodegenerative diseases, I fully understand the importance of early diagnostic and testing tools such as biomarkers and how they can positively impact patients’ treatment options, disease progression and survival probability. 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. Biomarker tests are being used more frequently as their accuracy and helpfulness has increased. 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. Patients dealing with neurodegenerative diseases like ALS already have astronomical costs and massive medical bills. 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 motor neurons lose connection with their muscles. In ALS, these neurons are found in the brain and spinal cord and are incredibly precious to the ability to carry out everyday tasks. Losing these critical neurons cause patients with ALS lose their ability to walk, talk, eat, and eventually breathe. Although there is no current cure for ALS, there are a couple drugs on the market that have been shown to slow the progression of the disease. These treatment options though are extremely costly, on top of the necessary and chronic tests and doctor visits that accumulate when you are living with ALS. 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. As a child someone I loved dearly had ALS and although our time with him was limited, we made the most of it. If there were tests like this years ago when he was diagnosed and fighting ALS we might have had more invaluable time together. As science evolved and more treatments and diagnostic tools are discovered, it's important that access to these tools also evolves and patients of all diseases have access to these tests without fear of accruing more medical debt.

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,

A handwritten signature in black ink that reads "Samia Pratt". The signature is written in a cursive, flowing style.

Samia Pratt
131 Pioneer Farm Way
Ellsworth, ME 04605