January 15, 2025

The Honorable Senator Donna Bailey
The Honorable Representative Kristi Mathieson
Committee On Health Coverage, Insurance and Financial Services

Re: Support for LD107 - An Act to Require Health Insurance Coverage for Biomarker Testing

Dear Chair Bailey, Chair Mathieson and members of the Health Coverage Insurance and Financial Services Committee,

On behalf of the ALS Association and the patients we serve in Maine, we express our support for LD107, which would require health insurance coverage for biomarker testing.

ALS or “Lou Gehrig’s” 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 for ALS, and an average person with ALS lives between 2-5 years.

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. While most current applications of biomarker testing are in oncology and autoimmune disease, there is research underway to benefit patients with other conditions including heart disease, neurological conditions like Alzheimer's disease, infectious disease, respiratory illness, and even ALS.

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.

Unfortunately, not all communities in Maine are benefitting from the latest advancements in biomarker testing and precision medicine. Patients who are older, Black, uninsured or Medicaid-insured, live in rural communities, and those who get their care in a community setting versus academic medical centers, are less likely to be tested for certain guideline-indicated biomarkers. Without action, lack of access to biomarker testing could increase existing disparities in health outcomes by race, ethnicity, income, and geography.

Currently it takes 12-14 months for someone to be diagnosed with ALS, meaning they are further along in their journey before they begin receiving treatment. With research on its way to identifying biomarkers for diseases like ALS, it is vital that biomarker testing is accessible to patients so they can receive a diagnosis earlier and get treated quicker.

The bottom line is that timely access to guideline-indicated comprehensive biomarker testing can potentially help achieve the triple aim of health care including better health outcomes, improved quality of life, and reduced cost. When people living with ALS are already losing so much of their lives to this devastating disease, they should not have to worry about losing access to the extra time with their loved ones and the benefits that these tests can eventually provide.

For these reasons we are supportive of **LD107**, which will require insurance coverage of biomarker testing. We thank you for your consideration and look forward to seeing this critical legislation move forward.

Sincerely,

Danielle Adams, MPH
Managing Director, Advocacy
ALS Association