



March 21, 2025

House Committee on Behavioral Health and Health Care

Oregon State Legislature

900 Court St, NE

Salem, OR 97301

RE: Support Treatment of ALS and HB 3421

Chair Nosse, Vice Chairs Javadi and Nelson, and members of the Committee:

ALS Northwest Supports HB 3421 and the potential for identifying and treating ALS through early identification of biomarkers.

Headquartered in Portland, ALS Northwest supports families throughout Oregon and Southwest Washington with a comprehensive range of care services for those living with Amyotrophic Lateral Sclerosis (ALS). Also known as Lou Gehrig's disease, ALS is a progressive neurodegenerative disorder that primarily affects motor neurons in the brain and spinal cord. While its exact cause remains unclear, some cases are linked to genetic mutations. Tragically, there is still no cure for ALS. Existing treatments and therapies are limited but can help manage symptoms and improve quality of life.

In 2024, ALS Northwest served 650 people living with ALS and has made over \$2.5 million in cumulative investments toward ALS research.

Diagnosing and treating ALS is exceptionally challenging, partly due to the disease's complexity and the variety of causes and origins—a concept known as disease heterogeneity. As research advances in understanding genetic forms of ALS and exploring potential treatments, biomarkers are emerging as critical tools. Fluid-based markers from spinal fluid, blood, and urine are promising avenues for developing diagnostic and prognostic methods to better identify and understand ALS.

HB 3421 is a well-crafted step towards using biomarkers to potentially identify ALS and address this heartbreaking and complex disease. HB 3421 limits coverage requirements for biomarkers to circumstances where evidence demonstrates the tool is useful and there's a viable treatment. We may not be there yet for ALS, but supporting this bill is a critical step in delivering hope for the ALS community moving forward.

Thank you for considering this important topic and we urge your support of HB 3421.

Thank you,

A handwritten signature in black ink, appearing to read "Cassy Adams".

Cassy Adams, MSW, LCSW

Executive Director