



Alone we are rare. Together we are strong.®

March 18, 2025

The Honorable Rob Nosse
Chair, House Committee on Behavioral Health & Health Care
Oregon State Legislature
900 Court Street NE
Salem, OR 97301

Re: Support for House Bill 3421 – Coverage for Biomarker Testing

Dear Chair Nosse and Members of the House Behavioral Health & Health Care Committee:

On behalf of the more than 30 million Americans living with one of the over 10,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes to share our support for House Bill 3421, legislation that would require access to biomarker testing, as specified.

With a more than 40-year history, NORD is the leading and longest-standing patient advocacy organization for the estimated 1-in-10 Americans living with a rare disease. An independent 501(c)(3) nonprofit, NORD is dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 355 patient organization members, is committed to improving the health and well-being of people with rare diseases by driving advances in care, research, and policy. NORD believes that all individuals with a rare disease should have access to high quality, affordable health care that is best suited to meet their medical needs.

Biomarkers are characteristics, such as radiographic abnormalities or biological molecules found in blood, tissue, or other bodily fluid that can be objectively measured to determine the sign of a condition or disease. The result of a biomarker test can be used to assess how well a patient responds to a treatment for a disease or condition, as well as determine the best course of action for a patient.ⁱ This can significantly improve patient outcomes; for instance, in rare cancers, including pediatric cancers, this can mean that treatments can be targeted specifically for the genetic or molecular makeup of the tumor.ⁱⁱ Biomarker testing allows for targeted care and precision medicine, thus decreasing the treatment time and increasing the likelihood of survivorship for patients.ⁱⁱⁱ While currently biomarker testing is often used in oncology, biomarker testing can benefit patients in many disease groups, including autoimmune diseases, and research is underway that may unlock benefits in other rare conditions.

Unfortunately, patient access to biomarker testing is often delayed or denied by health insurance plans. HB 3421 would require coverage for biomarker testing if the use of the test is supported by medical and scientific evidence, and provided in a manner that limits disruptions in care including the need for multiple biopsies or biospecimen samples.

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We urge you to support this legislation to ensure all patients can benefit from this quickly evolving aspect of precision medicine by swiftly passing HB 3421 out of the House Committee on Behavioral Health & Health Care. Thank you for your attention to this matter. For any questions, please contact me at lviscarra@rare diseases.org.

Sincerely,



Lindsey Viscarra
State Policy Manager
National Organization for Rare Disorders

ⁱ Biomarkers. ONS. (n.d.). Retrieved December 7, 2022, from <https://www.ons.org/genomics-taxonomy/biomarkers>

ⁱⁱ Biomarker testing for cancer treatment. National Cancer Institute. (n.d.). Retrieved December 7, 2022, from <https://www.cancer.gov/about-cancer/treatment/types/biomarker-testing-cancer-treatment#:~:text=Biomarker%20testing%20is%20a%20way,how%20certain%20cancer%20treatments%20work>.

ⁱⁱⁱ Biomarker testing for cancer treatment. National Cancer Institute. (n.d.). Retrieved December 7, 2022, from <https://www.cancer.gov/about-cancer/treatment/types/biomarker-testing-cancer-treatment#:~:text=Biomarker%20testing%20is%20a%20way,how%20certain%20cancer%20treatments%20work>.