



NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®

March 11, 2024

Joint Interim Standing Committee on Health and Human Services

Senator Fabian Doñate, Chair

Assemblyman David Orentlicher, Vice Chair

Senator Rochelle T. Nguyen

Assemblywoman Tracy Brown-May

Assemblyman Ken Gray

Assemblyman Brian Hibbetts

Assemblyman Duy Nguyen

Dear Chair Doñate, Vice Chair Orentlicher, and members:

My name is Lindsey Viscarra, and I'm the State Policy Manager for the Western Region at the National Organization for Rare Disorders (NORD). NORD is the leading independent advocacy organization representing the more than 30 million Americans living with a rare disease and their families. At NORD, we believe that all patients should have access to quality, innovative, and affordable health coverage that is best suited to their individual medical needs.

Rare disease patients face unique challenges in accessing an accurate diagnosis, appropriate medical care, and access to support services. The average length of time to an accurate diagnosis for rare disease patients is 7 years – we call it the diagnostic odyssey. The cost of this diagnostic odyssey is often physically, mentally, and financially devastating to patients and their families, including my own. Biomarkers show tremendous potential to help shorten this diagnostic odyssey for rare disease patients by enabling a more accurate diagnosis. Additionally, once an accurate diagnosis is obtained, the use of biomarker testing can support health care providers in making optimal treatment decisions, increasing the chances for a patient to have a good health outcome while reducing health system costs.

The National Organization for Rare Disorders urges you to remove the cancer only limitation for access to biomarker testing in Nevada, and allow patients suffering from other diseases to access the benefits of biomarker testing, including improved quality of life and reduced costs.

1779 MASSACHUSETTS AVENUE NW, SUITE 500
WASHINGTON, DC 20036
T 202-588-5700 ■ F 202-588-5701

7 KENOSIA AVENUE
DANBURY, CT 06810
T 203-744-0100 ■ F 203-263-9938

1900 CROWN COLONY DRIVE, SUITE 310
QUINCY, MA 02169
T 617-249-7300 ■ F 617-249-7301

rarediseases.org ■ orphan@rarediseases.org

NORD® and its icon are registered trademarks of the National Organization for Rare Disorders. NORD is a registered 501(c)(3) charity organization.

NORD will be happy to serve as a resource for you as you consider biomarker testing policies in Nevada. Please reach out via email at lviscarra@rarediseases.org if I can be of any assistance or answer any questions.

Sincerely,



Lindsey Viscarra
State Policy Manager, Western Region
National Organization for Rare Disorders



NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®