



April 4, 2023

The Honorable Sarah Peters
Chair
Assembly Committee on Health and Human
Services
Legislative Building, Room 3132
401 South Carson Street
Carson City, Nevada 89701-4747

The Honorable David Orentlicher
Vice Chair
Assembly Committee on Health and Human
Services
Legislative Building, Room 3132
401 South Carson Street
Carson City, Nevada 89701-4747

Re: Keep Assembly Bill 155 Relevant for All People with Rare Conditions

Dear Chair Peters and Vice Chair Orentlicher;

The National Organization for Rare Disorders (NORD) is the leading independent advocacy organization representing the millions of Americans affected by a rare disease. At NORD, we believe that all patients should have access to quality, accessible, innovative, and affordable health coverage that is best suited to their medical needs. On behalf of Nevadans with rare disorders, NORD has been proud to support A.B. 155, legislation that would expand access to biomarker testing. However, it is vital that A.B. 155 is not limited to one disease area in order for the legislation to fully benefit our community.

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. **That is why it is essential that A.B. 155 remain disease agnostic.**

Limiting the scope of A.B. 155 to cover only biomarker testing in cancers will dramatically lessen the impact of this legislation now and in the future and means that many patients will not

be able to benefit from future innovation in biomarker testing. This change would be detrimental to the rare disease community and would force NORD to reconsider our support for this legislation. We urge you to leave the scope of A.B. 155 as drafted to ensure all relevant patients can benefit from this quickly evolving aspect of precision medicine, and to swiftly advance the legislation out of your Committee.

Thank you for your attention to this matter. For any questions, please contact me at areed@rarediseases.org.

Sincerely,

Annissa Reed

Annissa Reed
Associate Director, State Policy
National Organization for Rare Disorders

CC: Members of the Assembly Committee on Health and Human Services

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>.

