



Alone we are rare. Together we are strong.®

May 29, 2024

The Honorable Patty Kim  
Chair, Committee on Insurance  
Pennsylvania House of Representatives  
38A East Wing P.O. Box 202103  
Harrisburg, PA 17120

**Re: NORD Supports House Bill 1754 (Mullins) – An Act Providing for Coverage for Biomarker Testing**

Dear Chair Kim,

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 1754 ([HB 1754](#)), legislation that would expand access to biomarker testing.

NORD is a unique federation of non-profits and health organizations dedicated to improving the health and well-being of people living with rare diseases. NORD was founded 41 years ago, after the passage of the Orphan Drug Act (ODA), to formalize the coalition of patient advocacy groups that were instrumental in passing that landmark law. NORD's mission has always been, and continues to be, to improve the health and well-being of people with rare diseases by driving advances in care, research, and policy. We believe that all patients should have access to quality, innovative, and affordable health coverage that is best suited to 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. 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. Biomarker testing allows for targeted care and precision medicine, thus decreasing the treatment time and increasing the likelihood of survivorship for patients. 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 1754 would require coverage for biomarker testing if the use of the test is supported by medical and scientific evidence. Furthermore, it would establish clear parameters

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and processes for utilization review, including prior authorization, to ensure limited disruptions in care for patients.

NORD urges you to support this legislation to ensure all patients can benefit from this quickly evolving aspect of precision medicine by swiftly passing HB 1754 out of the House Committee on Insurance. Thank you for your attention to this matter. For any questions, please contact me at [csheridan@rarediseases.org](mailto:csheridan@rarediseases.org).

Sincerely,



**Carolyn G Sheridan, MPH**  
*State Policy Manager, East*  
**National Organization for Rare Disorders**

CC:

Representative Kyle Mullins, Sponsor HB1754

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Yanira Feliz, Constituent Services Advisor, Chair Patty Kim