NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®

December 12, 2024

The Honorable Nellie Pou
Chair, Senate Committee on Commerce
100 Hamilton Plaza, Suite 1405
Paterson, New Jersey 07505

Re: NORD Supports Senate Bill 3098 (Vin) – An Act Providing for Coverage for Biomarker Testing

Dear Chair Pou,

On behalf of the more than 30 million Americans living with any of the over 10,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes to share our support for Senate Bill 3098 (S3098 (Vin)), legislation that would expand access to biomarker testing in New Jersey.

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. Biomarker testing helps assess how well a patient responds to treatment and can guide personalized care plans. For individuals with rare diseases, including rare cancers and autoimmune diseases, biomarker testing enables precision medicine that targets the unique genetic or molecular composition of their condition. This reduces treatment delays, improves outcomes, and in some cases, increases survivorship. While most commonly associated with oncology, research is rapidly advancing the use of biomarker testing across other disease states, including many rare conditions.

Despite its potential, patient access to biomarker testing is frequently delayed or denied due to insurance barriers. Senate Bill 3098 addresses these issues by requiring health insurers in New Jersey to cover biomarker testing with supported by medical and scientific evidence, including guidelines from nationally recognized clinical organizations. The bill also ensures coverage is implemented with minimal disruptions to patient care by establishing clear timelines for utilization review and prior authorization decisions. For example, non-urgent prior authorization requests must be processed within 72 hours, while urgent requests must be addressed within 24 hours.

This legislation is disease-agnostic, ensuring that all patients who could benefit from biomarker testing have access to this innovative diagnostic tool. Importantly, Senate Bill 3098 also helps bring advanced medical tools within reach for underserved populations by requiring no cost-sharing for Medicaid beneficiaries. This provision ensures that financial barriers do not prevent patients from accessing cutting-edge diagnostics.

NORD urges you to support Senate Bill 3098 and advance it out of the Senate Commerce Committee to ensure all people in New Jersey can benefit from this rapidly evolving aspect of medical care. Thank you for your attention to this matter and for your service to the State of New Jersey. For any questions, please contact me at csheridan@rarediseases.org.

Sincerely,

C Sheridan

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

CC:
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