NORD® RARE CANCER COALITION

Alone we are rare. Together we are strong.®

March 20, 2026

The Honorable Kathy Hochul Governor of New York State NYS State Capitol Building Albany, NY 12224	The Honorable Andrea Stewart-Cousins Majority Leader New York State Senate NYS State Capitol Building Albany, NY 12224	The Honorable Carl Heastie Speaker New York State Assembly NYS State Capitol Building Albany, NY 12224

RE: Oppose Proposed Rollback of Medicaid Coverage Criteria for Biomarker Testing in the Final Budget

Dear Governor Hochul, Leader Stewart-Cousins, and Speaker Heastie,

The undersigned organizations are members of NORD's Rare Cancer Coalition®, a national network of patient advocacy organizations united around a single reality: rare cancer patients face challenges that most people with cancer never encounter. Over 1 in 4 cancer diagnoses in the United States are rare[1]. Rare cancers account for 25% of all cancer deaths[1]. More than 90% of rare diseases, including rare cancers, lack an FDA-approved treatment[2]. We write to urge you to reject the proposed rollback of Medicaid coverage criteria for biomarker testing.

Rare cancers are extremely challenging to diagnose. Patients typically face numerous physician visits, misdiagnosis, and substantial delays before receiving an accurate diagnosis. These delays can be devastating emotionally, financially, and medically[3].[3] The 5-year survival rate is lower for people living with a rare cancer than for those diagnosed with a more common cancer. All pediatric cancers are rare[1]. These statistics describe real patients our organizations serve every day: people who have already waited too long, who have already exhausted options, and who cannot afford to lose access to the diagnostic tools that give their care direction.

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[1] National Cancer Institute, MyPART: About Rare Cancers. https://www.cancer.gov/pediatric-adult-rare-tumor/rare-tumors/about-rare-cancers

[2] *Tambuyzer E, et al. Therapies for rare diseases: therapeutic modalities, progress and challenges ahead.* Nature Reviews Drug Discovery. 2023. https://www.nature.com/articles/d41586-023-02492-x

[3] *DeSantis CE, Kramer JL, Jemal A. The burden of rare cancers in the United States.* CA: A Cancer Journal for Clinicians. 2017. https://onlinelibrary.wiley.com/doi/full/10.3322/caac.21400

New York's biomarker testing law was a landmark step for our community. The evidence criteria at its core, including nationally recognized clinical practice guidelines and peer-reviewed evidence, are the mechanism that ensures rare cancer patients are not excluded from coverage because their disease is too uncommon to appear in older standards. Rare cancers are precisely the conditions for which evolving guideline evidence matters most, because that evidence is often newer, harder won, and more recent than the evidence base for common cancers. Removing these criteria from the statute would delay diagnoses, foreclose treatment options, and ultimately shift costs onto patients and the Medicaid program alike.

We are aware of the divergent approaches in the current budget proposals and want to be clear about where our organizations stand:

- The Executive Budget's **elimination of all evidence criteria** would leave rare cancer patients' access to biomarker testing subject to arbitrary coverage determinations with no grounding in clinical science.
- The Assembly's proposal to **remove nationally recognized clinical practice guidelines and peer-reviewed evidence** as qualifying criteria is particularly dangerous for rare cancer patients. Guidelines from organizations like NCCN are often the primary, and sometimes only, evidentiary basis for coverage of rare cancer biomarker tests.
- The Senate's approach to **preserve all evidence criteria** is the right path forward for rare cancer patients, for Medicaid enrollees broadly, and for New York's ability to keep pace with a rapidly evolving field.

Our organizations represent patients who have fought for every tool available to them. Biomarker testing is one of those tools, and for many patients it is the one that made the difference.

We urge you to stand with the Senate's position and ensure the evidence criteria in New York's biomarker testing law remain fully intact. Thank you for your service to New York State

Sincerely,

On behalf of the NORD Rare Cancer Coalition® Member Organizations:

A Cure in Sight
Cholangiocarcinoma Foundation
EHE Foundation
Gallbladder Cancer Foundation
HPV Cancers Alliance
International Waldenstrom's Macroglobulinemia Foundation
National Leiomyosarcoma Foundation
NET Research Foundation
Pheo Para Alliance
Target Cancer Foundation
VHL Alliance

For questions regarding this letter, please contact Carolyn Sheridan, Associate Director of State Policy, NORD, at csheridan@rarediseases.org.