



**Support for S1287-A (Persaud)/A1296-A (Paulin)
Establishes a Permanent Rare Disease Advisory Council in the State of New York**

The sixty-three undersigned organizations representing individuals with rare diseases in New York, write in **support of S1287-A (Persaud)/A1296-A (Paulin)** which would establish a permanent and robust Rare

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Disease Advisory Council (RDAC) in the state, preserving the forum first established in 2019 for the 1.8 million New Yorkers living with a rare disease and their families.¹

As defined by the Orphan Drug Act, any disease or condition that affects fewer than 200,000 Americans is considered rare.² Overall, there are more than 10,000 known rare diseases, affecting an estimated 30 million Americans across a broad spectrum of medical conditions. Rare disease patients face many unique challenges every day, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition, to battling for fair insurance coverage of their treatment and care. However, due to small patient populations and the variety of rare diseases, it can be difficult for state government officials to have an in-depth understanding of the rare disease community's complex needs. This lack of awareness often contributes to the obstacles faced by rare disease patients and their loved ones.

New York State first established a Rare Disease Advisory Council in 2019, when A5762 (Paulin)/S4497 (Rivera) was signed into law. Pursuant to a Chapter Amendment, the Council was enacted as a temporary working group with a sunset two years following its signing. Legislative actions during the FY24 budget extended the lifecycle for an additional two years thus, the working group sunset effective December 20, 2023. On December 30, 2024, the Rare Disease Working Group published its final report, which included 20 distinct recommendations. Among these was a recommendation for New York to establish a "standing advisory group of rare disease patients and caregivers to collaborate with stakeholders and address the needs of the rare disease community."³

While New Yorkers with rare diseases benefit from services like newborn screening, mandated coverage of medical nutrition, and prescription cost-sharing protections, there remain many unmet needs within our community. The creation of a permanent New York State Rare Disease Advisory Council is the next logical step to building a more supportive foundation for the rare disease community in New York.

This year's legislation reflects critical updates to the proposed RDAC's duties and operations, ensuring that the Council will be even better equipped to address community needs. Updates include a new duty for the RDAC to provide advisory input to the Drug Utilization Review Board (DURB), as well as a requirement for the Council's recommendations to be incorporated into the State's Prevention Agenda and presented before the Health Equity Council. Additionally, clarifications to funding mechanisms will allow the RDAC to tap into funds already appropriated as part of the \$25M in investments for the rare disease community made in the FY25 Enacted Budget. These improvements position the RDAC to be a strong and impactful advocate for the rare disease community.

The undersigned organizations are particularly encouraged to see language included in these bills that will enhance what the working group has already accomplished like making the Council subject to Open Meetings Law, adding a duty that empowers the Council or the Department to identify priorities which will provide the group the flexibility needed to adapt to the ever-changing healthcare landscape, and finally a provision that allows the Council to tap into public, private and other available funding sources to support them in their work. The potential value of a permanent RDAC cannot be understated.

With diverse membership and broad community support, a New York RDAC will serve as a valuable resource as our health care system evolves. A strong RDAC can help relieve burdens on the state by

¹ [New York State Rare Disease Workgroup Report](#)

² [United States Food & Drug Administration, Rare Diseases at FDA](#)

³ [New York State Rare Disease Workgroup Report](#)

expeditiously delivering direct feedback, solutions, and resources to New York government decision makers with one community voice. Without an RDAC, New York laws and regulations that affect the rare community will be developed without the consultation of rare disease stakeholders, leaving this vulnerable population at greater risk for poor health and economic outcomes.

On behalf of the undersigned organizations, **we ask for your support in preserving the voice of the rare disease community in New York.** For any questions, please feel free to contact Lindsey Viscarra with the National Organization for Rare Disorders via email at lviscarra@raredisases.org. Thank you for your consideration.

Sincerely,

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The ALS Association
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American Cancer Society Cancer Action Network (ACSCAN)
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HCU Network America
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Hermansky-Pudlak Syndrome Network, Inc. (HPS Network)
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Hyper IgM Foundation
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Mellie J Foundation
MLD Foundation
MSUD Family Support Group
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The Myositis Association (TMA)
National Bleeding Disorders Foundation (NBDF)
National Fragile X Foundation (NFXF)
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Sarcoidosis of Long Island
Sickle Cell Advocates of Rochester (SCAR)
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Sickle Cell Warrior of Buffalo (SCWB)
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