NORD®
National Organization for Rare Disorders

Alone we are rare. Together we are strong.®

October 2, 2024

Dr. James V. McDonald M.D., M.P.H.
Commissioner, New York State Department of Health
Empire State Plaza
Corning Tower
Albany, NY 12237

Dear Commissioner McDonald,

On behalf of New York State's rare disease community, the National Organization for Rare Disorders (NORD) writes to ask for the **inclusion of a proposal to make New York State's Rare Disease Working Group a permanent and robust Rare Disease Advisory Council (RDAC)** as part of your response to the FY26 Call Letter from the New York State Budget Director Blake Washington.

NORD is committed to enhancing the health and wellbeing of individuals affected by rare diseases. With over 330 member organizations, we represent the voices of patients and caregivers impacted by the more than 10,000 known rare diseases. Our extensive advocacy efforts have played a critical role in establishing 29 state-level RDACs across the country, most recently in the State of California,[1] ensuring that the unique needs of rare disease communities are addressed through collaborative dialogue among stakeholders.

The Working Group in New York was first established by statute in 2019 but didn't become operational until March 2023 due to the State's unprecedented and critical response to the COVID-19 pandemic. That said, the group has still managed to serve as an essential platform for discussing best practices, raising awareness, and evaluating barriers to access for individuals living with rare diseases.

Now, **the statutory authority for the temporary workgroup has expired,[2]** and it will require administrative or legislative action for the Governor's intent to make the working group permanent to come to fruition.[3]

---

[1] NORD, September 30, 2024 **New California Law Establishes the Jacqueline Marie Zbur Rare Disease Advisory Council (RDAC)** https://rarediseases.org/california-establishes-rare-disease-advisory-council/

[2] Original Legislation, 2019 A5762 (Paulin)/S4497 (Rivera) Signed into Law as **Chapter 74 of the Laws of 2020** with extenders in FY23 HMH Part CC §9.

[3] **State of the State 2024**, Our New York, Our Future, Governor Kathy Hochul (p. 137)

NORD was thrilled to see the significant $25 million investment made last year into the rare disease community. This funding represents a strong commitment to addressing the needs of individuals living with rare diseases in New York. Making the RDAC permanent, as proposed in 2023-2024 legislative session bills S9724 (Persaud)/A10292-A (Paulin) is the final, essential step to fulfilling the promise made to this community.

We believe that making the RDAC permanent is crucial for the following reasons:

1. **Sustained Advocacy:** A permanent RDAC would enable ongoing engagement with the rare disease community, ensuring that their insights effectively inform public policies and programs.

2. **Data-Driven Decisions:** The Council would be empowered to conduct public hearings and surveys, gathering vital data on the needs and experiences of the rare disease community, thereby facilitating more effective policy development.

3. **Strategic Resource:** The RDAC would serve as a well-established resource representing the rare disease community, enabling the Department to consult with stakeholders as spending decisions are made, thereby ensuring that investments align with community needs.

4. **Enhanced Collaboration:** The diverse membership of the RDAC fosters a collaborative approach to addressing the complex challenges faced by the rare disease community.

5. **Public Accountability:** Making the RDAC subject to Open Meetings Law will ensure transparency and inclusivity, allowing for meaningful public participation in its discussions and decision-making processes.

Your extensive experience in public health, particularly in roles focused on health quality and safety, as well as your commitment to addressing healthcare disparities, aligns perfectly with the intent of the RDAC. A strong and permanent RDAC will be invaluable in proactively addressing the needs of New Yorkers with rare diseases, ensuring that their voices are heard, and their needs are met.

We respectfully urge you to include a proposal for the permanent establishment of the RDAC in your response to the FY26 Call Letter. Together, we can build a more supportive foundation for the rare disease community in New York.

Thank you for your attention to this important matter. We would welcome and appreciate an opportunity to discuss the proposal further with you or a member of your staff as you are putting your response as an agency together.

Sincerely,

C Sheridan

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

Lindsey Viscarra
State Policy Manager, West
National Organization for Rare Disorders

CC:
Angela Profeta, *Deputy Secretary for Health*, New York State Executive Chamber
Chloe Coffman, *Senior Advisor for Health*, New York State Executive Chamber
Kyle Kotary, *Assistant Commissioner, Public Affairs Group,* New York State Department of Health
Mischa Sogut, *Assistant Commissioner for Government Relations*, New York State Health Department