NORD®
National Organization
for Rare Disorders

Alone we are rare. Together we are strong.®

January 27, 2025

The Honorable Amy Paulin
Chair
Assembly Committee on Health
Legislative Office Building
Albany, NY 12248

The Honorable Roxanne Persaud
Chair
Senate Committee on Human Services
Legislative Office Building Rm.
Albany, NY 12248

Re: NORD Supports A1296 (Paulin)/S1287 (Persaud) – Establishes a Permanent Rare Disease Advisory Council in the State of New York

Dear Assemblymember Paulin and Senator Persaud,

The National Organization for Rare Disorders (NORD) is thrilled to share our support for your bill, A1296/S1287 and to convey our deepest gratitude for your support of the rare disease community. This legislation will establish a permanent and robust Rare Disease Advisory Council (RDAC) in the State of New York, preserving the forum first established in 2019 for the 1.8 million New Yorkers living with a rare disease and their families.[1]

NORD is a federation of non-profits and health organizations dedicated to improving the health and wellbeing of people living with rare diseases by driving advances in policy, research, and care. We have over 330 member organizations, which represent patients and caregivers living with one of the over 10,000 known rare diseases. For forty-one years, NORD has been at the forefront of advocacy for policies and programs such as the creation of state RDACs. Through Project RDAC, NORD is working to establish an effective RDAC in every state to help address the complex needs of the rare community at the state level. Rare Disease Advisory Councils currently serve 29 other states by connecting patients, caregivers, and other healthcare experts to focus on the exchange and development of knowledge and recommendations that improve the lives of those with rare diseases. This can range from helping to create databases on research, treatments, and treatment providers to helping develop public policies and support services which enable people with rare diseases to live healthier lives.

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 long-awaited 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."[2]

This legislation creates the Rare Disease Advisory Council within the New York State Department of Health to identify best practices, raise awareness regarding rare diseases, evaluate barriers to access to care, and to make recommendation to the Legislature and the Governor. Its diverse membership will

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[1] New York State Rare Disease Workgroup Report

[2] New York State Rare Disease Workgroup Report

include individuals with rare diseases, caregivers, patient organization representatives, healthcare providers, and members of the scientific, insurance, and biopharmaceutical communities. There are also positions for the Commissioner of Health (or their Designee) and the Superintendent of Financial Servies (or their Designee). Members are not to be compensated for their role on the Council but are entitled to per diem compensation and reimbursement of expenses related to their work. Unique to New York State, the bill allows for a previously convened body – whether dissolved or not – to be repurposed to fulfill the requirements of the bill. This would allow the working group to be called back together – significantly reducing the time the permanent Council will take to get operational and reduce the administrative burden on the Department.

The Council must meet within the first 180 days of enactment and quarterly thereafter as they work to address their prescribed duties. A notable provision of **A1296/S1287** is a duty that empowers the Council or the Department with the flexibility to identify additional priorities upon a majority vote of members. The RDAC will also be tasked with engaging with the public to assist the Council with a population survey of the needs of the rare community in New York. The design and dissemination of these population surveys are a cornerstone of the other Councils across the country and provide much-needed information on the experiences of rare patients in the state. 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.

Finally, NORD would like to draw attention to and share our most ardent support for two provisions of the bill; a provision that makes the Council meeting subject to Open Meetings Law and a provision that allows the Council to tap into public, private and other funding sources to support them in their work. Due to how the working group was set up it was not subject to requirements that allow for public input and participation in meetings. This made it difficult for the working group to incorporate the public voice into their work – which is a key component of these Councils across the country. Many Councils also face hurdles in funding their initiatives and language within this bill would allow the New York Council to get ahead of that problem by tapping into funds such as those already appropriated as part of the $25M in investments for the rare disease community made in the FY25 Enacted Budget.

With diverse membership and broad community support within New York State, including a diverse stakeholder group of over 70 individuals who played a critical role in shaping the language that makes this bill, a permanent and robust RDAC will serve as a valuable resource as our health care system evolves. A strong RDAC can help relieve burdens on the state by expeditiously delivering direct feedback, solutions, and resources to New York government decision makers with one community voice. Without an RDAC, laws and regulations that affect the rare community may be developed without the consultation of rare disease stakeholders, leaving this vulnerable population at greater risk for poor health and economic outcomes.

Thank you for sponsoring this important legislation. NORD remains a committed partner as this bill progresses. Please feel free to contact me at lviscarra@rarediseases.org for any questions or assistance.

Sincerely,

Lindsey

Lindsey Viscarra
State Policy Manager
National Organization for Rare Disorders

CC:
Leah Barber, Director of Grassroots Advocacy, National Organization for Rare Disorders