NORD®
National Organization
for Rare Disorders

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May 17, 2024

The Honorable Amy Paulin
Chair
Assembly Committee on Health
Legislative Office Building Rm. 822
Albany, NY 12248

Re: NORD Supports A10292 (Paulin) – Establishes a Permanent Rare Disease Advisory Council in the State of New York

Dear Chair Paulin,

The National Organization for Rare Disorders (NORD) is thrilled to share our support for your bill, A10292, and express our most sincere 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 estimated 1-in-10 New Yorkers living with a rare disease.

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 27 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. The work of New York's rare disease working group had only just begun. Due to the State's unprecedented and critical response to the COVID-19 pandemic, the group did not meet for the first time until March of 2023. As a result, New York's rare community has not had the opportunity to see their Council reach its full potential.

A10292 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. New York's RDAC would be made up of thirteen appointed members, representing a diverse set of stakeholders in the rare disease community, including individuals living with a rare disease, caregivers of a person with a rare disease, representatives of a rare disease patient organization, physicians, nurses or other healthcare providers with experiencing

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providing care to individuals with rare diseases, representatives from health insurance and biopharmaceutical companies, a member of the scientific and academic community engaged in rare disease research. 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 in fulfillment of their duties. 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 which would allow the working group to be called back together – significantly reducing time the permanent Council will take to get operational and hopefully reducing the administrative burden on the Department.

The Council must meet within the first ninety days of enactment and quarterly thereafter as they work to address six prescribed duties. A notable provision of A10292 is a seventh duty that empowers the Council or the Department to identify additional priorities upon a majority vote of members. The RDAC will be tasked with convening public hearings, making inquiries, and soliciting comments from 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. The legislation also requires the Council to provide testimony & comments on pending relevant legislation and rules and advise on policy matters related to patient access to, and quality of rare disease specialists, affordable and comprehensive health care coverage, relevant diagnostics, timely treatment, and other needed services, and state planning related to natural disasters or public Health emergencies.

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 available 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 private or public funds such as the $25M of critical investments into the rare disease community made as part of the FY25 Enacted Budget.

With diverse membership and broad community support within New York State, including a diverse stakeholder group of over 40 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. We hope you consider NORD a resource for you as this bill moves through the legislative process and look forward to working with you and your staff to improve the lives of rare disease patients and their families living in New York. If you have any questions or need further assistance, please contact Lindsey Viscarra at lviscarra@rarediseases.org.

Sincerely,

Lindsey

Lindsey Viscarra
State Policy Manager
National Organization for Rare Disorders