NORD®
National Organization
for Rare Disorders

RARE
NY

July 25, 2019

The Honorable Andrew M. Cuomo
Governor of New York State
NYS State Capitol Building
Albany, NY 12224

Re: Support for A 5762/S 4497 – New York Rare Disease Advisory Council

Dear Governor Cuomo,

On behalf of the 1-in-10 individuals in New York State (NYS) with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges you to sign Assembly Bill 5762 (A 5762) and Senate Bill 4497 (S 4497) into law. This legislation passed both chambers in the 2019 legislative session to establish a Rare Disease Advisory Council that would give a voice to the rare community in NYS government.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

Rare diseases are present across a broad spectrum of medical conditions. For example, all forms of pediatric cancer are considered rare, as are brain, pancreatic, ovarian, thyroid, and stomach cancers. Other examples of rare diseases include lysosomal storage diseases, blood disorders, eye diseases, and autoimmune disorders. For patients suffering from these and numerous other rare conditions, it can take several years to receive an accurate diagnosis and effective treatment. Further, only a handful of rare diseases are well-understood, with most not receiving sufficient attention or funding for research.

The New York Rare Disease Advisory Council will give rare disease patients a unified voice in our state government by providing them a forum to make recommendations to elected officials and other state leaders about pressing health care issues. From providing information on the provider-patient relationship to identifying best practices throughout the nation, the council will coordinate with legislators and other government leaders to improve public policy for the entire state. What is more, because this legislation requires broad participation from the different health care sectors present in New York – doctors, hospitals, insurers, manufacturers, and researchers are all represented on the council – it will also serve as an educational resource to all stakeholders about the ways in which rare disease patients interact with our health care system.

In creating this council, New York will be joining eight other states who have already enacted similar legislation in support of their rare disease community: Alabama, Connecticut, Illinois, Kentucky, Minnesota, Missouri, New Hampshire, North Carolina, and Pennsylvania.

Once again, on behalf of the New York rare disease community, we urge you to sign A 5762 and S 4497 into law. We look forward to working with your office to successfully enact the New York Rare Disease Advisory Council, which will provide incredible support for the state's rare disease community. We must give a voice to New Yorkers living with rare diseases – many of whom are too young or too sick to speak for themselves. For further questions, please feel free to contact us at rsher@rarediseases.org or mary.wootten@rareaction.org.

Sincerely,

/s/

Rachel Sher,
Vice President of Policy and Regulatory Affairs

Mary Wootten

Mary Wootten,
New York Rare Action Network Volunteer State Ambassador

CC:

Axel Bernable – Assistant Counsel to the Governor

Megan Baldwin – Assistant Secretary for Health