



April 4, 2019

Chairwoman Weinstein  
LOB 923  
Albany, NY 12248

**Re: Support for A 5762**

Dear Chairwoman Weinstein and Members of the Ways and Means Committee:

On behalf of the 1-in-10 individuals in New York with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges you to support A 5762, legislation that would establish a Rare Disease Advisory Council.

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 six other states who have already enacted similar legislation of support of their rare disease community: Alabama, Connecticut, Illinois, Kentucky, Missouri, North Carolina, and Pennsylvania.



We hope you consider the incredible support that a Rare Disease Advisory Council could provide for New York's rare disease community. Please give a voice to New Yorkers living with rare diseases – many of whom are too young or too sick to speak for themselves – by supporting A 5762.

Thank you for the opportunity to comment on this legislation.

Sincerely,

Tim Boyd,  
Director of State Policy

Mary Wootten,  
New York Rare Action Network Volunteer State Ambassador

CC: Members of the Ways and Means Committee