

January 5, 2021

The Honorable Gustavo Rivera  
Chairman  
Senate Committee on Health  
172 State Street, Capitol Building 502C  
Albany, NY 12247

The Honorable Amy Paulin  
Chairwoman  
Assembly Committee on Corporations, Authorities, and Commissions  
LOB 422  
Albany, NY 12248

**Re: Support for the New York Rare Disease Workgroup**

Dear Chairman Rivera and Chairwoman Paulin,

On behalf of the undersigned organizations representing individuals with chronic, acute, or rare diseases in the State of New York, we thank you for your work throughout 2020 to protect New Yorkers from COVID-19. We would also like to thank you for sponsoring Assembly Bill 5762 and Senate Bill 4497 in 2019 to establish a Rare Disease Advisory Council (RDAC). This important legislation was signed into law by Governor Cuomo on April 17, 2020 as a result of chapter amendment 74.

As you are aware, S.4497/A.5762 proposed to create an RDAC that would meet three times in each calendar year and was responsible for biennial reports. However, chapter amendment 74 of 2020 amended the statute to create a workgroup that sunsets in December of 2021. While we recognize the state is still facing unprecedented times during this COVID-19 pandemic, we write to urge you to contact New York Health Commissioner Howard Zucker to ask that a health department staff member be assigned to start the Rare Disease Advisory Workgroup and help swiftly implement this law consistent with the intent of the NYS Legislature. Establishing the Workgroup will give rare disease patients a unified voice in our state government and will be a valuable advisory body to elected officials and other state leaders on rare disease research, beneficiary access to treatments, and best practices for the care of those with rare diseases.

The patient community stands ready to assist as there is no greater time for this Workgroup to help address issues that the New York rare disease community faces in this or a future crisis. Rare diseases are present across a broad spectrum of medical conditions and their needs have not subsided during this crisis. For example, across this country, 79% of rare disease patients had a medical appointment cancelled and approximately 32% have had challenges accessing medical care and treatment.<sup>1</sup>

The Workgroup will represent enormous value to the state legislature and government by allowing them to directly hear from a diverse group of stakeholders interested in identifying and solving pressing challenges. In addition, the Workgroup would help relieve some of the burden from the state by expeditiously delivering direct feedback, solutions, and resources with one community voice.

In implementing this workgroup, New York would join thirteen other states that have already enacted and implemented similar legislation in support of the rare disease community and proven that a body like this can be an invaluable resource. Those states include: Alabama, Connecticut, Illinois, Kentucky, Massachusetts, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, Ohio, Pennsylvania, Tennessee, Utah, and West Virginia. Furthermore, NORD recently launched [Project RDAC](#) to help strengthen the existing workgroups or councils across the country and stands ready to assist with any additional information that would be helpful when contacting the Department of Health.

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<sup>1</sup> [https://rarediseases.org/wp-content/uploads/2020/11/NRD-2061-RareInsights-CV19-Report-2\\_FNL.pdf](https://rarediseases.org/wp-content/uploads/2020/11/NRD-2061-RareInsights-CV19-Report-2_FNL.pdf)

On behalf of the undersigned organizations, we thank you for your continued dedication to the rare disease community. Please feel free to contact Rose Gallagher, with the National Organization for Rare Disorders, at [RGallagher@rarediseases.org](mailto:RGallagher@rarediseases.org) with any questions. Thank you for your consideration.

Sincerely,

Adult Polyglucosan Body Disease Research Foundation  
Alliance for Patient Access  
American Cancer Society Cancer Action Network  
Association of Northeastern New York  
Bleeding Disorders Association of the Southern Tier  
Bleeding Disorders Hemophilia Association of New York  
Boomer Esiason Foundation  
Epilepsy Foundation of Northeastern New York  
Friedreich's Ataxia Research Alliance  
Galactosemia Foundation  
Global Healthy Living Foundation  
Hermansky-Pudlak Syndrome Network  
Highway of Hope  
Infusion Access Foundation  
Lupus and Allied Diseases Association, Inc.  
M-CM Network  
Mary Gooley Treatment Center  
Narcolepsy Network  
National Organization for Rare Disorders  
New York City Hemophilia Chapter  
New York State Bleeding Disorders Coalition  
New York State Sickle Cell Advocacy Network, Inc. (Formally QSCAN)  
The Oley Foundation  
Raymond A. Wood Foundation  
Western New York Blood Care  
Wilson Disease Association