January 15, 2021

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

Dear Governor Cuomo:

As the leading advocacy groups and healthcare providers representing patients with rare diseases, we thank your state health department for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. Respectfully, we encourage you to include individuals with rare diseases in addition to the primary caregivers of high-risk individuals as priorities in the administration of any FDA-approved or authorized COVID-19 vaccine.

Rare diseases typically have extensive comorbidities that can be present at birth or develop later in life. Additionally, many rare diseases are progressive and can cause physical, developmental, and cognitive disabilities. Manifestations can include cardiopulmonary dysfunction, disease, and abnormalities; neurological deficits such as seizures; chronic kidney disease; immunosuppression; poor growth; loss of muscle coordination; muscle weakness and pain; vision and/or hearing loss; gastrointestinal issues; intellectual and learning disabilities; autism spectrum disorder; and organ failure.[1] It is estimated 25-30 million individuals in the United States have a rare disease, of which many are life-threatening with limited treatment options.[2]

As rare disease organizations and healthcare providers, we strongly believe individuals living with a rare disease (>16 years of age) whose disabilities require hands-on caregiving and their caregivers should be included in high-risk population of the COVID-19 vaccination administration.[3] Due to the complexity of such disorders, our patients are at increased risk for poor outcomes due to infection with the novel coronavirus. The effects of COVID-19 could be devastating for these individuals and family members, both children and adults, who are already at a high risk for neurological and organ damage during times of extra stress. During the pandemic, these families have often lost numerous resources vital to their loved ones as well as delays in routine care management due to the risk of exposure.

To minimize the risk of exposure, we request including individuals and caregivers who live with and/or provide care for individuals with rare diseases in high-risk populations COVID-19 vaccination administration. The caregivers are essential to the overall health, safety, and security of individuals with rare diseases – if these essential caregivers contract COVID-19, isolation from those they care for could cause severe, irreversible damage.[4]

We welcome the opportunity to discuss our request further.

For questions, please contact Ashley Pounders, MSN, FNP-C, Director of Medical Affairs at the Tuberous Sclerosis Alliance, apounders@tsalliance.org or (301) 562-9890.

Respectfully submitted,
Angelman Syndrome Foundation
Autism Science Foundation

Batten Disease Support and Research Association
BPAN Warriors
Bridge the Gap – SYNGAP Education and Research Foundation
Jeffrey R. Buchhalter, MD
CACNA1A Foundation
Child Neurology Foundation
Wendy Chung, MD, PhD - Kennedy Family Professor of Pediatrics and Medicine, Chief, Clinical Genetics, Columbia University
Coalition to Cure CHD2
COMBINEDBrain
CURE Epilepsy
CureSHANK
Cute Syndrome Foundation
Danny Did Foundation
Dravet Syndrome Foundation
Dup15q Alliance
Epilepsy Foundation
FamiliesSCN2A Foundation
Kyle Fink, PhD - Institute for Regenerative Cures, UC Davis School of Medicine
FOXG1 Research Foundation
Global Genes
Glut1 Deficiency Foundation
GRIN2B Foundation
Hope for Hypothalamic Hamartomas
Hope for ULD
International Foundation for CDKL5 Research
KCNQ2 Cure Alliance
KIF1A.ORG
LGS (Lennox-Gastaut Syndrome) Foundation
NORSE Institute
PACS1 Syndrome Research Foundation
PCDH19 Alliance
Phelan-McDermid Syndrome Foundation
Project 8p
RARE-X
Rare Epilepsy Network (REN)
RASopathies Network
Ring14 USA
Jill Silverman, PhD - MIND Institute, UC Davis School of Medicine
SLC6A1 Connect
SNAP25 Foundation
STXBP1 Foundation
SynGAP Research Fund
Tbc1d24 Foundation
TESS Research Foundation for SLC13A5 Epilepsy

The Brain Recovery Project: Childhood Epilepsy Surgery Foundation
The Schinzel-Giedion Syndrome Foundation
Tuberous Sclerosis Alliance
Wishes for Elliott/DEE-P Connections

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[1] "FAQs About Rare Diseases." *National Center for Advancing Translational Sciences (NCATS)*. Updated 11/30/2017. Accessed via web: https://rarediseases.info.nih.gov/diseases/pages/31/faqs-about-rare-diseases#:~:text=How%20many%20rare%20diseases%20are,at%20between%2025-30%20million.

[2] Ibid.

[3] Landers, Scott D. et.al. "COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State" https://doi.org/10.1016/j.dhjo.2020.100969

[4] Wong, Allen, Carl, Tyler, and Emily Johnson. "Joint Position Statement on Equity for People with Intellectual and Developmental Disabilities Regarding COVID-19 Vaccine Allocation and Safety." *American Academy of Developmental Medicine & Dentistry.* Updated 12/9/2020. Accessed via web: https://static1.squarespace.com/static/5cf7d27396d7760001307a44/t/5fd9690f9e3b1725e3d0d3e2/1608083731221/Covid19Vaccine-IDD-Statement.pdf.