January 25, 2021

Dear Provider,

As the leading national organization that represents individuals and families with Duchenne muscular dystrophy, a rare neuromuscular disease, Parent Project Muscular Dystrophy (PPMD) asks that you provide priority access to COVID-19 vaccines to individuals with Duchenne aged 16 years and above as well as their families and in-home health care workers.

The Advisory Committee on Immunization Practices (ACIP) provides advice and guidance to the Director of the CDC regarding use of vaccines. On December 22nd, ACIP updated their vaccine allocation recommendations for Phase 1c, to include persons aged 16-64 years with high-risk medical conditions. These recommendations provide guidance for federal, state, and local jurisdictions.

People living with Duchenne are considered to be at higher risk for complications from COVID-19 according to the CDC. This is due in part to the standard of care, which includes use of corticosteroids to slow disease progression. As people with Duchenne also have cardiac and pulmonary impairment, this further increases their risk, making them more prone to complications requiring invasive ventilatory support, prolonged inpatient hospitalization, or even death.

PPMD advocates for priority COVID-19 vaccine access to individuals with Duchenne muscular dystrophy given their underlying health conditions may put them at greater risk for serious illness and complications. Also, we ask that their home health aides and family members (who often share caregiving duties) receive preferential access to a COVID-19 vaccine.

Thank you in advance for your support of individuals with Duchenne and their caregivers as you prepare for the distribution of COVID-19 vaccines.

Sincerely,

Pat Furlong
Founding President and CEO
Parent Project Muscular Dystrophy

Rachel Schrader MS, APRN, CPNP-PC
Vice President, Clinical Care and Education
Parent Project Muscular Dystrophy