

December 16, 2020

Director's Office
Illinois Department of Public Health
Springfield Headquarters Office
525-535 West Jefferson Street
Springfield, IL 62761

Re: Access to COVID-19 Vaccines for the Neuromuscular Disease Community

Dear Director's Office of the Illinois Department of Public Health,

In service of the over 300,000 Americans living with a neuromuscular disease (NMD), the 20 undersigned patient advocacy organizations thank Illinois Department of Public Health for its ongoing efforts to distribute COVID-19 vaccinations equitably and effectively. We respectfully write to encourage you to include individuals living with NMDs in Phase 1 of Illinois's vaccination administration of any FDA-approved or authorized COVID-19 vaccine. As set forth herein, the experiences, comorbidities, and impacts of NMDs should serve as qualifying factors.

Neuromuscular diseases are a wide range of conditions varying in symptom severity and patient experience, but generally implicate the peripheral nervous system resulting in progressive muscle weakness affecting both skeletal muscles and the muscles of internal organs. Consequently, progressive muscle weakness and mobility issues as well as cardiac, pulmonary, and digestive complications are common. Disorders in this category include amyotrophic lateral sclerosis (ALS), muscular dystrophies, and spinal muscular atrophy (SMA) along with many myopathies and mitochondrial diseases, among others.

We strongly believe that individuals over 16 years of age living with a neuromuscular disease should be included in Phase 1 of Illinois's vaccination administration due to the complexity of the multi-system impact of NMDs that results in co-morbidities that cause a high risk for adverse COVID outcomes. Consequently, we request Illinois to include those with NMDs in Phase 1 of your official distribution schedule.

In addition to other organ and system involvement, cardiac complications are common in individuals living with neuromuscular disease as an impact of the disorder. Additional common symptoms in neuromuscular diseases could lead to a higher risk to negative outcomes from COVID-19. For example, NMDs can weaken the pulmonary muscles and diaphragm over the progression of the disease, increasing the risk of severe pulmonary infection, and making the outcome of COVID-19 particularly dangerous.¹ Individuals with NMDs often are prescribed corticosteroids to combat the muscle weakening, and the CDC has listed individuals who take corticosteroids as "might be at an increased risk" for severe COVID-19 due to the associated weakening of the immune system.² Additionally, individuals with certain NMDs, such as

¹ Cao, Michelle, et. Al, "Pulmonary Support for Neuromuscular Disease Patients During COVID19 Pandemic, Retrieved From https://www.mda.org/sites/default/files/2020/03/MDA-Guidelines-for-Healthcare-Pros_PulmonarySupport-Neuromuscular-Disease-Patients-COVID-19.pdf

² Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions, Retrieved from: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>

myasthenia gravis and Lambert-Eaton myasthenic syndrome (LEMS) require immunosuppressants to treat the disease, leaving them more vulnerable to contracting severe COVID-19.³ CDC also lists neurological conditions as a potential increased risk factor for severe COVID-19.⁴

In summary, we request that Illinois include individuals with neuromuscular diseases in Phase 1 of its COVID-19 vaccination distribution timeline as the cardiac, pulmonary, neurological, sometimes immunological, and potential additional risk factors put individuals with neuromuscular diseases at higher risk for severe COVID-19. We welcome the opportunity to discuss our request further. For questions, please contact Paul Melmeyer, Director of Regulatory Affairs at the Muscular Dystrophy Association, at advocacy@mdausa.org.

Sincerely,

ALS Association
Answer ALS
Charcot-Marie-Tooth Association
Coalition to Cure Calpain 3
Cure CMD
CureDuchenne
Cure SMA
Cure VCP Disease, Inc.
Friedreich's Ataxia Research Alliance (FARA)
FSHD Society
I AM ALS
LGMD Awareness Foundation, Inc.
Les Turner ALS Foundation
Little Hercules Foundation
MitoAction
Muscular Dystrophy Association
Myasthenia Gravis Foundation of America (MGFA)
Parent Project Muscular Dystrophy
Team Gleason
United Mitochondrial Disease Foundation

³ Jacob, Sujaih, et. Al. Guidance for the management of myasthenia gravis (MG) and Lambert-Eaton myasthenic syndrome (LEMS) during the COVID-19 pandemic: Journal of the Neurological Sciences: Volume 412, 116803, May 15, 2020 <https://doi.org/10.1016/j.jns.2020.116803>.

⁴ Centers for Disease Control and Prevention, (2020, Oct. 16) People with Certain Medical Conditions