



Les Turner ALS Foundation
5550 W. Touhy Avenue, Suite
302
Skokie, IL 60077-3254

847 679 3311

lesturnerals.org

Dr. Ngozi Ezike
Director, Illinois Dept. of Public Health
535 W. Jefferson Street, Floor 5
Springfield, IL 62761-5058

January 8, 2021

Dear Dr. Ezike:

As we are awaiting more formal guidance from the CDC Advisory Committee on Immunization Practices (ACIP), preliminary plans have been developed for a phased approach toward COVID-19 vaccine distribution. As the State of Illinois moves through the phases, it is our hope that those individuals living with neuromuscular diseases, like Amyotrophic Lateral Sclerosis (ALS), are given priority access to COVID-19 immunizations due to the high-risk nature that the disease and their situations present.

The current State of Illinois plan has stated that Phase 1a should include residents of long-term care (LTC) facilities. It is widely accepted that residents of LTC facilities are at higher risk because they have underlying poor health and many caregivers coming from the outside on rotating shifts.

Phase 1c addresses adults with 'High Risk Medical Conditions.' The guidance from the State refers to those living independently at home but are noted to have common conditions that increase their risk of having major complications in the setting of COVID infection. This includes obesity, diabetes, COPD, heart conditions, chronic kidney conditions, cancer, solid organ transplant and sickle cell disease.

As representatives of the neuromuscular disease (NMD) care community, we would like to point out that although our patients are typically community dwelling, they are similar to those living in congregant environments in that they employ shifts of caregivers. In fact, they are at higher risk because often PPE is difficult for these caregivers to access as they are not part of large institutions. (<https://www.cdc.gov/coronavirus/2019-ncov/hcp/direct-service-providers.html>)

Given these concerns, we believe NMD patients should have been vaccinated in Phase 1a, but this did not occur. It would be logical then to assume that these patients would be vaccinated in Phase 1c, but at this time they are not expressly listed on the approved list. We know that in the setting of NMD, the most common cause of morbidity and mortality is pneumonia.¹ In the

¹ Philippe Corcia, Pierre-François Pradat, François Salachas, Gaëlle Bruneteau, Nadine le Forestier, Danielle Seilhean, Jean-Jacques Hauw & Vincent Meininger (2008) Causes of death in a post-mortem series of ALS patients, Amyotrophic Lateral Sclerosis, 9:1, 59-62, DOI: 10.1080/17482960701656940

setting of COVID our patients are often underserved because the bedrock of NMD respiratory therapy (non-invasive ventilation and cough assist devices) is often not allowed in hospital COVID units because of concern for aerosol particle generation (AGP). For all of these reasons, we feel that those with NMD should be on the Phase 1c list.

In summary, we would ask that you consider the following:

- 1) Add home-based caregivers (often family members) to the Phase 1a list
- 2) Add neuromuscular disease patients to the Phase 1c list
- 3) Consider adding visiting nurses, palliative care teams, or community health teams to provide IN HOME vaccination so that home bound patients and their caregivers with NMD can receive vaccination.

In addition, the Les Turner ALS Foundation, an Illinois nonprofit operating since 1977, has partnered with 19 other neuromuscular disease organizations, led by the Muscular Dystrophy Association (MDA), to help ensure that those living with neuromuscular disease are given priority when it comes to access to COVID-19 immunization and treatments. As part of this large group of neuromuscular advocacy groups, joint letters were sent to each state's department of public health in December asking that they prioritize people with neuromuscular disease in their vaccine rollout plans. Our letter to the Illinois Department of Public Health is attached for reference.

Thank you so much for your attention and concern for those impacted by neuromuscular disease. Please feel free to reach out to us with any questions that you may have or if we can be of help in any way.

Sincerely,

Andrea Pauls Backman, MBA
CEO, Les Turner ALS Foundation

Lisa Wolfe, MD
Professor of Pulmonary and Neurology at Northwestern University
Director of Respiratory Care, Shirley Ryan Ability Lab

Senda Ajroud-Driss, MD
Associate Professor of Neurology at Northwestern University
Director of the Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine

John Coleman III, MD
Associate Professor of Pulmonary and Neurology at Northwestern University
Board of Directors, Les Turner ALS Foundation

Robert Kalb, MD
Joan and Paul Rubschlager Professor of Neurology at Northwestern University
Chief of Neuromuscular Disease, Feinberg School of Medicine
Director of the Les Turner ALS Center at Northwestern Medicine