



February 11, 2021—sent via email and USPS

Governor Mike DeWine  
Riffe Center  
77 S High St  
30<sup>th</sup> floor  
Columbus, Ohio 43215

**Re: Access to COVID-19 Vaccines for People with ALS**

Dear Governor DeWine:

The ALS Association Northern Ohio Chapter and Central & Southern Ohio Chapter respectfully request that you ensure people living with ALS in Ohio receive the COVID-19 vaccine at the earliest possible phase and that their caregivers be treated as frontline health care workers who are immediately eligible to be vaccinated. **People with ALS are inherently among the highest risk populations for contracting and dying from COVID-19, therefore, we request they be specifically included in the current 1b group who are eligible for vaccination.**

**New data from the Veterans Administration on January 28, 2021 confirmed that veterans with ALS who contract COVID-19 are three times more likely to die than veterans with COVID-19 who do not have ALS (OR 2.96, p 0.004).** The CDC [website](#) names ALS in its list of people with certain neurological medical conditions that might be at an increased risk of severe illness from COVID-19. Taken together, the path forward could not be clearer: people with ALS should be eligible to receive the COVID-19 vaccine in group 1b, regardless of their age.

	Number with COVID Positive cases excluding active cases	Number Deceased	% Deceased Excluding active cases
General VA Patients*	192,690	8,838	4.3
VA Patients with an ALS Diagnosis**	59	8	12.7

\*<https://www.accesstocare.va.gov/Healthcare/COVID19NationalSummary>

\*\*Spinal Cord Injuries and Disorders (SCI/D) COVID-19 Summary Report

ALS takes away the ability to walk, speak, swallow and eventually, to breathe. Most people with ALS die from respiratory failure, a circumstance that is severely exacerbated by COVID-19's respiratory effects. ALS symptoms can start in any part of the body, but the disease has a devastating impact on the muscles required for breathing. Most people with ALS need respiratory support equipment, including ventilators. With an average age of onset of ALS is between 40 and 70, and an average age of 55 at the time of diagnosis, people with ALS are also at high risk of contracting COVID-19 due to age.



**Given what people with ALS face in terms of this disease noted above, we also urge you to recategorize caregivers as frontline health care workers who are immediately eligible to be vaccinated.** Caregivers provide essential support with all activities of daily living for people with ALS and serve as the link with medical personnel. Finally, we urge you to develop the means to vaccinate people who may not be able to leave their homes to be vaccinated.

Thank you for your attention to this important request. The ALS Association's nationwide network of chapters and certified ALS clinics in Ohio stand ready to assist you in the effort to vaccinate people living with ALS and their caregivers as soon as possible.

Sincerely,

Marlin Seymour

A handwritten signature in black ink that reads "Marlin Seymour".

Executive Director  
The ALS Association Central & Southern Ohio Chapter  
1170 Old Henderson Rd, Suite 221  
Columbus, Ohio 43220

Mary Wilson Wheelock

A handwritten signature in black ink that reads "Mary Wilson Wheelock".

Executive Director  
The ALS Association Northern Ohio Chapter  
6155 Rockside Rd # 403  
Independence, OH 44131

Cc:

John Joseph, State of Ohio Immunization Program Manager

Dr. John Novak, MD, Director, The ALS Association Certified Center of Excellence at OhioHealth ALS Clinic—Columbus

Dr. Robert Neel, MD, Director, University of Cincinnati-ALS Multidisciplinary Clinic —Cincinnati

Dr. Erik Pioro, MD, PhD, FRCP (C) and Dr. Rebecca Kuenzler, MD, Co-Directors, The ALS Association Certified Center of Excellence at Cleveland Clinic—Cleveland

Dr. Stephen Selkirk, MD, Director, The ALS Association Certified Center of Excellence at The Louis Stokes VA Medical Center—Cleveland

Dr. Bashar Katirji, MD, FACP and Dr. Komal Sawlani, MD, Co-Directors, The ALS Association Partner Clinic at University Hospitals Case Medical Center—Cleveland