

February 4, 2021

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Norris Cochran
Acting Secretary
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Rochelle Walensky, MD, MPH
Director
Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30329

Re: New Data: ALS Veterans 3X More Likely to Die from COVID

Dear Acting Secretary Cochran and Director Walensky:

On behalf of the more than 20,000 Americans living with ALS, The ALS Association requests that CDC recategorize ALS as one of the conditions that are at increased risk of severe illness from the virus that causes COVID-19. Further, we request that people with ALS receive the vaccine during the earliest possible phase, and that their caregivers also be treated as frontline health care workers who are immediately eligible to be vaccinated.

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). While the CDC [website](#) currently names ALS in its list of people with certain neurological medical conditions that **might be at increased risk** of severe illness from COVID-19, given this new data it is essential that ALS be recategorized as one of the conditions that **are at increased risk** of severe illness from COVID-19. Taken together, the path forward could not be clearer: people with ALS should receive the COVID-19 vaccine at the earliest possible phase.

	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's respiratory effects. ALS symptoms can start in any part of



OUR VISION: Create a world without ALS.

OUR MISSION: To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

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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 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 stand ready to assist you in the effort to vaccinate people living with ALS and their caregivers as soon as possible.

Sincerely,



Calaneet Balas
President and CEO
The ALS Association
als.org

Cc:
Advisory Committee on Immunization Practices