

February 23, 2021

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Docket No. CDC-2021-0008
c/o Attn: ACIP Meeting
Centers for Disease Control and Prevention
1600 Clifton Road NE, MS H24-8
Atlanta, GA 30329-4027

RE: Request to Update COVID-19 Vaccine Allocation Recommendations Following New VA Data and Family Caregiver Determinations

Dear Members of the Advisory Committee on Immunization Practices:

On behalf of the more than 20,000 Americans living with ALS, The ALS Association requests that the Advisory Committee on Immunization Practices (ACIP) and the Centers for Disease Control and Prevention (CDC) prioritize people with ALS and their caregivers for COVID-19 vaccination. New data from the Veterans Administration (VA) confirms 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. As a result, we request that:

- People with ALS be prioritized for vaccination as early as possible,
- Family caregivers be recategorized as health care frontline essential workers eligible for immediate vaccination,
- Guidance be published to provide the COVID-19 vaccine to people that are homebound due to one of the conditions that are at increased risk of severe illness from COVID-19.

New Veterans Administration Data on ALS Mortality Due to COVID-19

We request that ACIP recommend that people with ALS be prioritized for COVID-19 vaccination as early as possible. 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).

	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



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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Additionally, we request that CDC's website be updated to recategorize ALS as one of the medical conditions that are at increased risk of severe illness from COVID-19. 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-19¹. The new VA data confirms that people with ALS should be recategorized on the CDC website into the latter category.

ALS Family Caregivers Are Essential Frontline Health Care Workers

We request that family caregivers of people with ALS be recategorized as health care frontline essential workers eligible for immediate vaccination. Family caregivers provide essential care for people with ALS. Recognizing the importance of family caregivers, on February 3, the VA decided to provide vaccines to family caregivers who are enrolled in the VA's Comprehensive Assistance for Family Caregivers Program.² While the current policy limits vaccine distribution to caregivers of veterans with a VA disability rating of 70% or higher, veterans with ALS fall into this category and therefore their family caregivers are eligible to receive the vaccine right now.

Family caregivers often provide people with ALS the same level of care that paid caregivers offer. While CDC's Interim List of Categories of Essential Workers Mapped to Standardized Industry Codes and Titles currently includes all "paid and unpaid persons serving in healthcare settings who have the potential for direct or indirect exposure to patients or infectious materials" and non-healthcare workers "essential to maintain critical infrastructure and continue critical services and functions", these definitions do not explicitly include family caregivers.³ As a result, only a few states and municipalities such as San Diego, California have prioritized family caregivers for vaccination.^{4,5}

¹ Centers for Disease Control and Prevention. (2020, February 11). *People with Certain Medical Conditions*. <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>

² Stump, A. (2021, February 9). *How Veterans, designated caregivers can get COVID-19 vaccine from VA*. VAntage Point. <https://blogs.va.gov/VAntage/84404/veterans-designated-caregivers-can-get-covid-19-vaccine-va/>

³ Centers for Disease Control and Prevention. (2020a). *Categories of Essential Workers | COVID-19 Vaccination | CDC*. <https://www.cdc.gov/vaccines/covid-19/categories-essential-workers.html>

⁴ Mapp, L. J. (2021, February 16). *Family caregivers now eligible for vaccination, but some of their loved ones are not - The*. San Diego Union-Tribune.

<https://www.sandiegouniontribune.com/caregiver/news-for-caregivers/story/2021-02-16/family-caregivers-now-eligible-for-vaccination-while-some-care-recipients-are-not>

⁵ San Diego Public Health Services. (2021, February 2). *Health Advisory Update #25: Coronavirus Disease 2019 (COVID-19) Vaccine Updates*. San Diego County Government. https://www.sandiegocounty.gov/content/dam/sdc/hhsa/programs/phs/cahan/communications_documents/02-02-2021.pdf

Together with VA's new data showing veterans with ALS who contract COVID-19 are three times more likely to die than veterans with COVID-19 who do not have ALS, it is clear there is an urgent need for ACIP and CDC's to explicitly prioritize people with ALS and their family caregivers any vaccine allocation recommendations. The VA's decision to prioritize vaccines for family caregivers demonstrates the need for the same practices to be extended outside of the Veterans Health Administration. Individual states' decisions to make this determination further reinforces the need for national alignment with updated CDC allocation recommendations.

Innovative Vaccination Delivery Solutions Needed for Homebound Patients

We request that ACIP and CDC promptly develop guidance for providing the COVID-19 vaccine to people that are homebound due to one of the conditions that are at increased risk of severe illness from COVID-19. The Centers for Medicare and Medicaid Services recognizes that a person is "homebound" when it requires considerable and taxing effort to leave home."⁶ A person with ALS who is paralyzed and dependent on a ventilator would meet this definition.

As a progressive disease, the care needs of people with ALS intensify as different body systems are affected. As mobility and respiratory challenges accelerate, the need for at-home health care as well as personal care services for activities of daily living becomes critically important. National guidance is needed to ensure homebound patients at increased risk of severe illness from COVID-19 are provided the vaccine as safely and quickly as possible.

About ALS and The ALS Association

ALS, or amyotrophic lateral sclerosis, is a progressive neurodegenerative disease that 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.

The ALS Association is the largest private funder of ALS research in the world. We fund global research collaborations, assist people with ALS and their families through our nationwide network of chapters and certified clinical care centers, and advocate for better public policies for people with ALS. Our mission is 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.

⁶ Centers for Medicare and Medicaid Services. (2020, November 6). *Medicare Benefit Policy Manual Chapter 7 - Home Health Services*. Page 23. <https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/bp102c07.pdf>

A key aspect of our work is to mitigate the harms of ALS, including on caregivers and families. Based on this commitment, we have provided feedback and recommendations for your consideration as you update COVID-19 vaccine allocation recommendations to the CDC.

Conclusion

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. Please contact Kathleen Sheehan, Vice President of Public Policy (ksheehan@alsa-national.org / 202-464-8645) with any questions on these comments or for additional information.

Sincerely,



Neil Thakur, Ph.D.
Chief Mission Officer
The ALS Association
als.org