

*Officers*

Chair  
Sue Gorman

Vice Chair  
Mark Calmes

Treasurer  
Connie Houston

Secretary  
Scott Kauffman

Lawrence R. Barnett  
Founding Chairman  
1913-2012

*Trustees*

Jinsy Andrews, M.D., MSc

Millie Arnold

Eugene Brandon, Ph.D.

Tom Carroll

Fred DeGrandis

Larry Falivena

Keith A. Gary, Ph.D.

Clifton (Cliff) Gooch, M.D.

Christi Kolarcik, Ph.D.

John P. Krave, Esq.

Tobin M. Kucharski

Lou Libby, M.D.

J. Thomas "Tommy" May

Kenneth Menkhaus, Ph.D.

Warren Nelson

Judy Pratt, D.M.D.

Charles Robinson, D.Sc., P.E.

Wendy Schriber, Esq.

Kevin Spinella, Esq.

Mark Stancil

David Van de Riet

President and CEO  
Calaneet Balas

December 21, 2020

Robert R. Redfield, Director  
Centers for Disease Control and Prevention  
Advisory Committee on Immunization Practices  
1600 Clifton Road, N.E., Mailstop H24-8  
Atlanta, GA 30329

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

Dear Director Redfield:

On behalf of the more than 20,000 people living with ALS in the United States, we are grateful for your efforts to arrest the COVID-19 pandemic. I am writing to request respectfully that you reinforce the CDC's guidance to states to specify that people living with ALS should receive the COVID-19 vaccine at the earliest possible time.

The CDC website specifies that people with certain underlying medical conditions are at increased risk for severe COVID-19 illness. Neurological conditions, including ALS, are mentioned under this category. However, people living with ALS fear that their state may not recognize their increased risk because the mention of ALS as high-risk condition is not prominent in the state distribution guidelines. We request that guidance to the states reinforce that people living with ALS receive the vaccine as early as possible.

People in mid-to-late stages of ALS require considerable support from caregivers and family members, including around-the-clock care for people on ventilator support. For that reason, we also urge you to support priority vaccine administration to ALS caregivers and to promote home administration of the vaccine for people whose advanced disease progression makes it difficult or impossible for them to leave their home.

ALS takes away the ability to walk, speak, swallow and eventually, to breathe. 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, and die due to respiratory failure. The average age of onset of ALS is between 40 and 70, with an average age of 55 at the time of diagnosis. However, cases of the disease do occur in younger people.



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.

NATIONAL OFFICE • 1300 Wilson Boulevard, Suite 600, Arlington, VA 22209 • PHONE 202.407.8580 FAX 202.464.8869 • [als.org](http://als.org)

The ALS Association is the only national nonprofit organization fighting ALS on every front. We lead the way in global research, assist people with ALS through a nationwide network of chapters and coordinate multidisciplinary care through certified clinical care centers. The ALS Association's chapters provide a full range of services to people living with ALS and families including expert assistance on how to secure health care and social services, liaison with multidisciplinary ALS clinics, critically important support groups and much more.

The ALS Association, including our 39 chapters and network of ALS clinics across the country, stands ready to assist you in the effort to vaccinate people living with ALS. Thank you for your urgent attention to this important request. We look forward to hearing from you soon.

Sincerely,



Calaneet Balas  
President and CEO  
The ALS Association

Cc:

Mary Beth Hance, Centers for Medicare and Medicaid Services  
Doran Fink, MD, Ph.D, Food and Drug Administration  
Mary Rubin, MD Health Resources and Services Administration  
Tammy Beckham DVM, Ph.D., Office of Infectious Disease and HIV/AIDS  
Policy  
John Beigel, M.D., National Institutes of Health