March 20, 2020

The Honorable Nancy Pelosi
Speaker of the House
1236 Longworth House Office Building
Washington, DC 20515

The Honorable Kevin McCarthy
House Republican Leader
2468 Rayburn House Office Building
Washington, DC 20515

The Honorable Mitch McConnell
Senate Majority Leader
317 Russell Senate Office Building
Washington, DC 20510

The Honorable Chuck Schumer
Senate Democratic Leader
322 Hart Senate Office Building
Washington, DC 20510

Dear Speaker Pelosi and Leaders McConnell, McCarthy, and Schumer:

The ALS Association urges Congress to include the Safeguarding Medicare Access to Respiratory Therapy (SMART) Act (H.R. 4945) and the ALS Disability Insurance Access Act (H.R. 1407/ S. 578) in the emerging legislation responding to the COVID-19 pandemic or as part of the upcoming “extenders” package for expiring health care programs. The SMART Act will protect access to noninvasive ventilators (NIV) for vulnerable people living with ALS, and the ALS Disability Insurance Access Act will ensure that they are able to receive their Social Security Disability Insurance (SSDI) check without waiting to satisfy an arbitrary five-month waiting period. Together, these bills will protect access to vital respiratory therapy and much-needed financial aid during the COVID-19 pandemic.

ALS is a neurodegenerative disease with no known cause, no cure and limited treatments that do not stop its progression. The disease destroys nerve cells in the brain and the spinal cord resulting in progressive paralysis with an average life expectancy of three to five years after diagnosis. Most people with ALS are diagnosed between the ages of 40 and 70. People with ALS will suffer respiratory distress as the disease progresses and require NIV for home use to avoid costly institutional care. In addition, people with ALS are an extremely high-risk population for COVID-19, a virus with dangerous respiratory implications for people with ALS.

People with ALS lose their jobs and employer-based insurance while costs for their medical care skyrocket. Timely access to SSDI and Medicare benefits is critically important. While people living with ALS qualify for Medicare immediately thanks to Congress waiving the 24-month waiting period in 2000, their SSDI payment is still delayed for five months.

**Protect Access to Ventilators**

Noninvasive ventilators allow people with ALS to remain in their own homes and avoid costly institutional care and potential exposure to COVID-19. Unfortunately, the Medicare program included NIVs in the competitive bidding program, which will reduce...
access to not only NIVs but also to respiratory therapists who are critically important in calibrating NIV equipment to meet the specific needs of each patient.

We had serious concerns about patient access to NIVs under competitive bidding even before the COVID-19 pandemic, but given the fact that the most serious symptoms of this virus are respiratory in nature, that concern is greatly magnified. All potential barriers to ventilators must be eliminated in order to ensure stable access to critical ventilation technology for all Medicare beneficiaries during this pandemic and beyond.

The ALS Association, respiratory physicians and therapists have strongly urged the Centers for Medicare and Medicaid Services (CMS) to immediately reverse its decision to include NIVs in competitive bidding to no avail. Because CMS has been unresponsive, we urge Congress to include the SMART Act (H.R. 4945) to halt competitive bidding as part of any COVID-19 or other public health legislation to protect access to respiratory therapy.

Provide Financial Aid to People with ALS

COVID-19 has created economic distress for every American, but the impact of the virus is much harder for people with ALS and their families. ALS is a financially devastating diagnosis to receive, costing an average of more than $1.4 million over the course of the disease. The economic impact and job loss of COVID-19 will be particularly acute not only for people living with ALS but also their family members who provide both caregiving and financial support. In addition to facing this terrible disease, timely access to SSDI and Medicare benefits is essential to mitigate the impact of COVID-19 on people with ALS and their families to the maximum extent possible.

The ALS Association is grateful that Congress is looking for ways to help all Americans cope with COVID-19 as part of an economic stimulus. We urge Congress to include the ALS Disability Insurance Access Act (H.R. 1407/ S. 578) in any economic stimulus package dealing with the COVID-19 pandemic to waive the arbitrary five-month waiting period for SSDI for people with ALS.

Conclusion

On behalf of The ALS Association and the more than 20,000 people with ALS that we serve, we urge you to include the SMART Act (H.R. 4945) and the ALS Disability Insurance Access Act (H.R. 1407/ S. 578) in the emerging legislation responding to the COVID-19 pandemic or as part of the upcoming “extenders” for expiring health care programs. These actions will provide important protections to access to ventilatory therapy for all Medicare beneficiaries and provide immediate financial aid to one of the health care system’s most costly and fragile patient populations.

The ALS Association would welcome the chance to discuss how we can help people with ALS who need home respiratory therapies both in relation to COVID-19 and beyond, and economic assistance that will help bridge finances for people impacted by
the disease. Please contact Abram Bieliauskas, associate director of government affairs, if you would like to discuss our recommendations or if there is additional information we can share with you about how people with ALS are being impacted by COVID-19. We stand ready to help Congress and the Administration in any way we can.

Sincerely,

Calaneet Balas