January 25, 2018

The Honorable Eric D. Hargan
Acting Secretary
Department of Health and Human Services
Humbert Humphrey building
200 Independence Avenue, S.W.
Washington, D.C. 20201

Re: Request for Information on “Promoting Healthcare Choice and Competition Across the United States”

Dear Acting Secretary Hargan:

On behalf of the undersigned organizations, we would like to bring to your attention an issue that requires the immediate and thoughtful attention of staff at the Centers for Medicare and Medicaid Services – patient access to supplemental oxygen. As patient and provider groups that serve the needs of patients who require supplemental oxygen, we are united in concern that the health of patients is at risk because of the quality and availability of supplemental oxygen.

As background, supplemental oxygen is standard medical therapy for people who are unable to maintain appropriate blood oxygen saturation during sleep or activities of daily living due to respiratory or cardiac disease. Research has demonstrated the value of supplemental oxygen therapy in reducing respiratory symptoms and in reducing morbidity and mortality. In practical terms, supplemental oxygen allows many patients to more fully participate in life activities including employment outside of the
home, raising children, participation in community activities, travel, or just independently living at home.

The undersigned organizations can say without exaggeration that supplemental oxygen is a matter of life and death.

Problems faced by patients and prescribers include:

- The current CMS required prescription for supplemental oxygen is obsolete and incompatible with several FDA approved Portable Oxygen Systems, resulting in receipt of oxygen systems different than that prescribed by the patient’s physician
- Lack of access to liquid oxygen, despite contractual obligations by the patient’s Durable Medical Equipment provider,
- Slow or no resolution of oxygen equipment problems, including broken oxygen systems and missing oxygen equipment (masks and tubing);
- Problems with timely and sufficient oxygen refill delivery.
- Inadequate education and training with respect to the patient’s individual system
- Lack of testing of oxygen levels on the equipment delivered to the patient

These problems are not just anecdotal observations, but are system-wide problems suffered by supplemental oxygen users across the U.S. The scope of these problems are fully documented in a publication in the Annals of the American Thoracic Society (see attached). In the year following the conduct of the attached study, there have been increased instances of problems faced by patients in rural areas of the country, a subject that is currently being studied by the Government Accountability Office.

As you are no doubt aware, addressing the problems in the delivery of supplemental oxygen services under the Medicare and Medicaid programs will require cooperative action by Congress, the Administration, patients and providers. But we fear no action will transpire until the Department of Health and Human Services and the Centers for Medicare and Medicaid Services fully recognize the severity of the problems faced by patients who require supplemental oxygen.

We look forward to working with you and your staff to better understand the scope and urgency of problems suffered by respiratory patients who require supplemental oxygen therapy.

Sincerely,

Undersigned organizations
Cc: Seema Verma, CMS Administrator

Alpha-1 Foundation

American Association for Respiratory Care

American Lung Association

American Thoracic Society

COPD Foundation

National Association for Medical Direction of Respiratory Care

Pulmonary Fibrosis Foundation

Pulmonary Hypertension Association

Respiratory Health Association

The LAM Foundation

US COPD Coalition