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* Diagnosed Alpha-1
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March 21, 2020

Dear Member of Congress:

I am writing on behalf of the Alpha-1 Foundation to ask that you and your House colleagues act to assure that patients with Alpha-1 Antitrypsin Deficiency (AATD) who are covered by Medicare Part B are able to access their infusion treatments at home. Individuals with AATD fall into the category of those at high risk during the SARS-CoV-2 virus pandemic. Reducing exposure for these individuals is the highest priority for the Alpha-1 Foundation.

AATD is a rare genetic condition leading to low levels of the important anti-inflammatory protein alpha-1 antitrypsin. Individuals with AATD are predisposed to progressive lung and liver disease. Alpha-1 Augmentation therapy for Medicare Part B patients is administered in hospitals or a physician office setting on a weekly basis. But the safest place for an individual with AATD during the COVID-19 pandemic is to receive their treatment at home. We have watched the CDC, WHO and White House COVID-19 Pandemic Task Force review the list of high-risk individuals as those with pre-existing kidney, heart and lung disease. Image the risk associated for those with a genetic form of Chronic Obstructive Pulmonary Disease (COPD). Since the approval of intravenous augmentation therapy with plasma-derived alpha-1 antitrypsin protein (generic: alpha-1 proteinase inhibitor, human) the survival, quality of life, and overall health of individuals with lung disease due to AATD has been dramatically improved.

During this pandemic it is essential that augmentation therapy is administered on a weekly basis to keep our population as healthy as possible. For those who have private insurance home infusion is the standard of care. Every day we hear from Medicare patients who are skipping infusions because they are terrified to present themselves at a medical center.

These concerns are dramatically magnified by the SARS-CoV-2 virus pandemic. With ill patients flocking to medical facilities with known or suspected COVID-19 infections, and patients with AATD at particularly high risk of severe disease should COVID-19 infection occur, it is imperative that CMS reevaluate its policy regarding home infusion of these treatments. With home infusions, the risks of infection can be more easily mitigated with careful decontamination of surfaces and skin by both the patient and their infusion nurse and the potential exposure of self-isolated patients can be minimized.

We strongly urge that intravenous infusions of alpha-1 antitrypsin augmentation therapy be released from the prohibition of home infusions and that CMS covers both the medication and its administration at home as it currently does for administration in healthcare facilities.

I look forward to your response.

Sincerely,

Miriam O'Day
President & CEO
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