The John W. Walsh Alpha-1 Home Infusion Act

Topline: This bill allows Alpha-1 rare disease patients to continue receiving critical in-home infusion treatment covered by Medicare.

Background: This successful policy was adopted administratively during the COVID pandemic as a temporary benefit but needs authorization from Congress to continue long-term. This is a patient access problem, and the Alpha-1 Foundation worked with Congress to find a solution facing Medicare beneficiaries who are unable to obtain home infusion coverage through Medicare. Specifically, the legislation will establish a permanent home infusion benefit in the Medicare Part B program specifically for Alpha-1 patients.

What is Alpha-1 Antitrypsin Deficiency?
Alpha-1 Antitrypsin Deficiency is a rare disease caused by a hereditary condition. Without treatment, this condition may result in serious lung disease in adults and/or liver disease in infants, children, and adults. Because Alpha-1 is genetic, Alpha-1 lung disease is sometimes called “genetic COPD.” Alpha-1 Antitrypsin Deficiency is treated by FDA approved augmentation therapies. Therapy slows but not reverses the progression of the lung destruction associated with this disorder.

Why is this legislation needed?
With the onset of the COVID-19 pandemic, the Alpha-1 Foundation alerted the Centers for Medicare and Medicaid Services (CMS) about the need for augmentation infusions to be administered in a safe site of care and offer protection from exposure to the deadly COVID virus, since Alpha-1 patients are significantly more susceptible to lung diseases. CMS agreed that there would be detrimental health effects on Alpha-1 patients of skipping infusions because of the risk of possible exposure to COVID-19 when going to a hospital infusion suite or a physicians’ office. CMS responded rapidly with the flexibility within the billing and payment system for Alphas to receive home infusions under Medicare Part B or Medicare Part D. Because of the lack of CMS guidance on reimbursement for the treatment, items, and services, the temporary benefit was not accessible for many patients.

What would the bill do?
The new Medicare Part B benefit would provide a reimbursement structure for augmentation therapy, intravenous administration kits, and up to 2 hours of nursing services. An Alpha-1 patient who is on Medicare should not have to choose between skipping needed therapy or exposure to a potentially fatal virus which preys on those with pulmonary issues.

*John W. Walsh* was the legendary founder of the Alpha-1 Foundation. John Walsh’s leadership and passion helped to shape the Alpha-1 Foundation into a successful organization. By his perseverance and hard work, John Walsh improved the lives of every Alpha-1 patient in the United States and around the world.

If you have any questions or your boss would like to cosponsor the bill, please contact Sean Smith at 55001 or sean.smith@mail.house.gov