



March 22, 2020

Dear Members of Congress:

On behalf of the 25 to 30 million Americans with one of the over 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) asks that, as you continue your work on the COVID-19 aid package, you and your colleagues act to assure that rare disease patients covered by Medicare Part B are able to access critical life-saving infusion treatments at home.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

Typically, rare disease patients receive their infusion treatments in hospitals, health centers, and doctors' offices. But now, in the face of the COVID-19 pandemic, these patients are at risk. Increasingly patients are unable to access their critical medications because these locations are either closed, not accepting non-COVID-19 patients, or they are being told to shelter in place.

Rare disease patients throughout the United States are anxious about barriers to accessing their infusions medicines or venturing out into the community, potentially to facilities where people are gathering for COVID-19 related testing and care, when they have been expressly warned against such contact. Their underlying conditions often leave patients immune-compromised putting them at high risk of contagion and serious illness.

Many patients are terrified to leave their home for scheduled infusions for fear of contracting COVID-19, heeding the warnings of government and public health officials that they avoid groups of people and those suffering symptoms as they themselves are at a high risk of infection.

Patients are experiencing disruptions of their critical infused medications, as well as basic, yet essential medicines and treatment, at a cost to their immediate and long-term health and well-being. It is critical that rare disease patients who are Medicare recipients are able to receive their medications at home during this crisis through appropriate providers and clinical staff with the expertise to administer these drugs safely, and do so with full personal protective equipment (PPE) and training to prevent the transfer of COVID-19 infection to patients or among home care personnel.

While Medicare has a home health benefit and home infusion benefit, drug administration services are covered for only a limited set of Part B drugs under these benefits. Likewise, Part B drug payment is only available for a limited set of drugs in the home setting. It is imperative that Medicare coverage of all Part B drugs and their related administration costs be made temporarily available in the home setting to allow beneficiaries access to home injection and infusion of these drugs.

NORD calls on Congress to provide improved access to needed treatments to avoid additional serious illness and unnecessary loss of life due to this crisis, by expanding the Medicare Home Infusion benefit to allow all Medicare patients across the United States to remain in their homes and receive necessary medications while the emergency declaration is in effect.

It is essential that any legislation intended to address COVID-19 related health care priorities provide temporary coverage of Part B drugs and biologicals furnished in the home.

Thank you very much for your consideration of our views.

Sincerely,

A handwritten signature in black ink that reads "Rachel Sher". The signature is written in a cursive style with a large, prominent initial "R".

Rachel Sher
Vice President, Policy and Regulatory Affairs