

November 13, 2023

Congresswoman Doris Matsui  
2311 Rayburn House Office Building  
Washington, DC 20515

Congressman Adrian Smith  
502 Cannon House Office Building  
Washington, DC 20515

Subject: Support HR 3017 – the PI Post Acute Access Act

Dear Representatives,

The undersigned organizations, representing an array of stakeholders, including patients, healthcare providers, product manufacturers, and caregivers, **express gratitude for your leadership and introduction of H.R. 3017, the PI Post Acute Access Act**, which will allow Medicare beneficiaries with primary immunodeficiencies to access their lifesaving immunoglobulin (Ig) treatments when they require rehabilitation care in a skilled nursing facility (SNF). Enacting this bill into law would address a deficiency in the existing Medicare coverage and payment policy that today is forcing beneficiaries with PI to choose between accessing their Ig medications or receiving needed skilled nursing care, a choice no beneficiary should be forced to make.

Primary immunodeficiencies (PIs) are a group of over 450 rare, chronic conditions in which part of the body's immune system is missing or does not function correctly. The National Institutes of Health estimates that approximately 500,000 individuals in the United States have a PI. These conditions stem from hereditary genetic defects and can affect individuals of all ages, genders, and ethnic backgrounds. Fortunately, with proper medical care, many people with PI can lead full and independent lives. For a significant portion of these individuals, this care includes lifelong infusions of immunoglobulin (Ig), medications that restore the antibodies people with PI are unable to produce.

Based on an analysis conducted by the Immune Deficiency Foundation, it is estimated that approximately 250 individuals with PI require admission to SNFs each year for rehabilitation care needs. While Medicare currently covers Ig therapy for beneficiaries with PI in a home setting, the single lump sum or daily bundled payment that Medicare pays when beneficiaries are admitted to SNFs is insufficient to cover the expenses associated with Ig medications, including both the costs of the drug and the nursing services needed to administer it. This means that if beneficiaries with PI need SNF care, they often cannot receive their Ig medications or are not admitted to the SNF in the first place.

Congress has recognized these challenges associated with certain therapies by excluding their cost from the per diem payment, enabling SNFs to bill separately for this care. For example, Congress has done this for certain chemotherapy medications as well as blood clotting factors used to treat bleeding disorders. While 250 beneficiaries may seem small compared to the broader Medicare population, rectifying this issue would substantially and positively impact health outcomes. Additionally, by ensuring beneficiaries with PI can access medications to bolster their immune systems, the policy would reduce the higher costs associated with hospitalizations and other interventions that are often utilized when these patients become ill.

**We thank you for recognizing the needs of the PI community and acting by leading H.R.3017, the PI Post Acute Access Act.** We hope this legislation can be enacted into law this Congress and offer our full support.

Sincerely,

American Academy of Allergy, Asthma & Immunology (AAAAI)

American Health Care Association (AHCA)

CSI Pharmacy

CSL Behring

Grifols

Hemophilia Federation of America

Immune Deficiency Foundation

Jeffrey Modell Foundation

National Association of Specialty Pharmacy

National Bleeding Disorders Foundation

Plasma Protein Therapeutics Association (PPTA)

CC: The Honorable Cathy McMorris Rodgers

The Honorable Frank Pallone

The Honorable Jason Smith

The Honorable Richard Neal