

January 9, 2018

The Honorable Paul Ryan
Speaker of the House
United States Congress
H-232, The Capitol
Washington, DC 20515

The Honorable Nancy Pelosi
Minority Leader
United States Congress
H-204, The Capitol
Washington, DC 20515

Dear Speaker Ryan and Leader Pelosi:

On behalf of all Medicare beneficiaries who are impacted by primary immunodeficiency diseases (PI), I am writing to urge Congress to enact legislation to establish a temporary Medicare home infusion services payment as soon as possible. Specifically, I urge the House and Senate to pass the **Medicare Home Infusion Therapy Access Act** as either a standalone bill or as part of a larger Medicare or omnibus legislative package.

This legislation is urgently needed to fix a problem created in late 2016 when Congress established a new Medicare home infusion benefit effective January 2021, but at the same time changed the reimbursement for these drugs effective January of last year. This set up a four-year gap during which reimbursement levels are largely insufficient to cover the nursing, education, training and monitoring services that are needed to ensure beneficiaries safely and effectively self-administer life-saving therapies such as subcutaneous intravenous immunoglobulin (SCIG) that are infused using Durable Medical Equipment (DME).

PI diseases are a group of more than 300 rare and chronic disorders in which a person's immune system is missing or functions improperly. There are no cures for PI diseases, but thankfully immunoglobulin (Ig) therapy delivered intravenously (IVIG) or subcutaneously (SCIG) restores these missing antibodies to enable impacted persons to fend off infections. Beneficiaries receiving SCIG therapy use an infusion pump to administer their treatment several times a week while beneficiaries receiving IVIG are typically infused every three to four weeks for a longer period of time.

Because of the payment gap created in late 2016, some Medicare beneficiaries with PI were notified last year that their home infusion provider would no longer be offering such services. As this issue continues to linger, we are very concerned that additional home infusion providers will soon reach similar conclusions resulting in sizeable access challenges for our population of immune-compromised beneficiaries.

S. 1738 seeks to remedy part of this problem by establishing a temporary services payment for two years – 2019 and 2020 – while the Centers for Medicare and Medicaid Services (CMS) engages in the rulemaking necessary to establish the full benefit. The provision passed the House as part of a Medicare Part B legislative package last July by unanimous voice vote, and the Senate bill has nearly 30 bipartisan cosponsors.

We are grateful for this previous activity and for the tremendous amount of bipartisan support that exists behind this legislation and the work of many members and staff on this issue. But we

urge you to complete this important work by ensuring this much-needed piece of legislation is enacted into law as soon as possible.

We thank you for considering this request. If you have any questions or if you would like to discuss this topic directly, please have your staff contact Larry LaMotte, Vice President, Public Policy at llamotte@primaryimmune.org or 443-632-2552.

Sincerely,

A handwritten signature in blue ink that reads "John G. Boyle". The signature is written in a cursive style with a large, stylized initial "J".

John G. Boyle
President & CEO

January 9, 2018

The Honorable Mitch McConnell
Majority Leader
United States Congress
317 Russell Senate Office Building
Washington, DC 20515

The Honorable Chuck Schumer
Minority Leader
United States Congress
322 Hart Senate Office Building
Washington, DC 20515

Dear Leader McConnell and Leader Schumer:

On behalf of all Medicare beneficiaries who are impacted by primary immunodeficiency diseases (PI), I am writing to urge Congress to enact legislation to establish a temporary Medicare home infusion services payment as soon as possible. Specifically, I urge the House and Senate to pass the **Medicare Home Infusion Therapy Access Act** as either a standalone bill or as part of a larger Medicare or omnibus legislative package.

This legislation is urgently needed to fix a problem created in late 2016 when Congress established a new Medicare home infusion benefit effective January 2021, but at the same time changed the reimbursement for these drugs effective January of last year. This set up a four-year gap during which reimbursement levels are largely insufficient to cover the nursing, education, training and monitoring services that are needed to ensure beneficiaries safely and effectively self-administer life-saving therapies such as subcutaneous intravenous immunoglobulin (SCIG) that are infused using Durable Medical Equipment (DME).

PI diseases are a group of more than 300 rare and chronic disorders in which a person's immune system is missing or functions improperly. There are no cures for PI diseases, but thankfully immunoglobulin (Ig) therapy delivered intravenously (IVIG) or subcutaneously (SCIG) restores these missing antibodies to enable impacted persons to fend off infections. Beneficiaries receiving SCIG therapy use an infusion pump to administer their treatment several times a week while beneficiaries receiving IVIG are typically infused every three to four weeks for a longer period of time.

Because of the payment gap created in late 2016, some Medicare beneficiaries with PI were notified last year that their home infusion provider would no longer be offering such services. As this issue continues to linger, we are very concerned that additional home infusion providers will soon reach similar conclusions resulting in sizeable access challenges for our population of immune-compromised beneficiaries.

S. 1738 seeks to remedy part of this problem by establishing a temporary services payment for two years – 2019 and 2020 – while the Centers for Medicare and Medicaid Services (CMS) engages in the rulemaking necessary to establish the full benefit. The provision passed the House as part of a Medicare Part B legislative package last July by unanimous voice vote, and the Senate bill has nearly 30 bipartisan cosponsors.

We are grateful for this previous activity and for the tremendous amount of bipartisan support that exists behind this legislation and the work of many members and staff on this issue. But we

urge you to complete this important work by ensuring this much-needed piece of legislation is enacted into law as soon as possible.

We thank you for considering this request. If you have any questions or if you would like to discuss this topic directly, please have your staff contact Larry LaMotte, Vice President, Public Policy at llamotte@primaryimmune.org or 443-632-2552.

Sincerely,

A handwritten signature in blue ink that reads "John G. Boyle". The signature is written in a cursive, flowing style.

John G. Boyle
President & CEO