May 3, 2024

The Honorable Brian Fitzpatrick
271 Cannon House Office Building
Washington, DC 20515

Dear Congressman Fitzpatrick,

On behalf of our organizations and the more than 30 million Americans living with rare diseases, we would like to thank you for introducing H.R. 5397, the Joe Fiandra Access to Home Infusion Act of 2023. We strongly support this legislation and are encouraged that it passed out of the Energy and Commerce Committee by a vote of 46-0 in December 2023. We hope that this legislation will continue to gain support and become law so that it can help patients as soon as possible.

Our organizations are patient-focused non-profits dedicated to improving the lives of individuals with rare diseases. We strongly believe that H.R. 5397 will improve care for many Medicare beneficiaries by expanding access to infused medications at home, when appropriate.

In 2016, Congress passed the 21st Century Cures Act, which included a new home infusion therapy (HIT) benefit for patients receiving at-home care through the Medicare Part B Durable Medical Equipment benefit. While we appreciate the improvements to care provided by the new HIT benefit, critical gaps remain in this benefit that prevent patients from accessing care at home when administration by a healthcare provider (HCP) is required.

Under the current home infusion benefit, a Medicare Fee-for-Service patient who needs regular infusions through an ambulatory infusion pump is denied coverage of infusions of certain drugs in the home. To receive coverage, they must travel to a hospital outpatient department, infusion center, or their physician’s office for these infusions. To be clear, this is only a requirement in Medicare Fee-for-Service, and patients with Medicare Advantage or commercial plans can receive these same HCP-administered infusions at home. At its core, this is an equity issue for our community.

This requirement is a barrier to care and an additional burden for many patients. Traveling to receive treatment requires transportation, which may entail long journeys for patients and their caregivers. Such travel can be uncomfortable or even dangerous for some patients. Providing patients with a choice to receive their infusions at home would alleviate this burden for patients and their caregivers and put the decision-making power in the hands of patients and their physicians.

Patients in the rare disease community face tremendous odds every single day. Their lives and the lives of their loved ones are often consumed by the condition, especially for those facing limited mobility or other challenging manifestations of their rare disease. H.R. 5397 provides an important option for patients who do not have the opportunity to make a lot of choices in the course of their treatment.

We strongly support H.R. 5397 and look forward to working with you to ensure that patients have access to the home infusion that they so critically need and deserve. Thank you again for your work on behalf of the rare disease community.

Sincerely,

Amyloidosis Foundation
Amyloidosis Support Groups
Amyloidosis Research Consortium
EveryLife Foundation for Rare Disorders
Fabry Support & Information Group
Infusion Access Foundation
International Society for Mannosidosis and Related Disorders (ISMRD)
Myasthenia Gravis Association
National MPS Society
National Organization for Rare Disorders
National Fabry Disease Foundation
NorCal Bay Area Amyloidosis Patient Support Group
Sacramento Area Amyloidosis Group (SAAG)
Sacramento/Central Valley Amyloidosis Patient Support Group