



February 24, 2020

The Honorable Darin LaHood  
United States House of Representatives  
Washington, D.C. 20515

The Honorable Brian Higgins  
United States House of Representatives  
Washington, DC 20515

The Honorable Debbie Dingell  
United States House of Representatives  
Washington, DC 20515

The Honorable Gus Bilirakis  
United States House of Representatives  
Washington, DC 20515

Dear Representatives LaHood, Higgins, Dingell and Bilirakis,

As the national organizations representing individuals with hemophilia and related bleeding disorders and the hemophilia treatment centers (HTCs) that care for them, we strongly support and urge swift Congressional action on The Hemophilia SNF Access Act. This critical legislation will address the existing barriers to accessing skilled nursing facility (SNF) care for the bleeding disorder patient community.

There are fewer than 1,000 Medicare beneficiaries living with inherited bleeding disorders and, today, they are denied access to SNF care. A person with a bleeding disorder may be referred to a SNF after a hospitalization for surgery to address severe joint damage caused by repeated bleeding into their joints, co-morbidities of HIV/AIDS and hepatitis, or other procedures related to aging. SNFs are often the most medically appropriate setting for post-acute care because they provide short-term, intensive, inpatient rehabilitative services and have the medical and nursing expertise to manage complications. Moreover, they provide a level of care beyond what is available to individuals treated at home.

Access to SNF care is typically denied because the current bundled payment a SNF receives is insufficient to cover the significant costs of treatments needed by people with bleeding disorders to enable their blood to clot. Since hemophilia and related bleeding disorder daily treatment costs well exceed the per diem rate for the highest-level SNF stay, any SNF willing to accept bleeding disorder patients would incur significant financial losses. As a result, our patients typically cannot access SNF care – requiring them to stay in the acute hospital inpatient setting longer, increasing costs for taxpayers. Alternatively, they may be referred to other settings with suboptimal care delaying improvement and increasing the likelihood for hospital readmission.

This legislation will address this problem by adding treatments for hemophilia and related bleeding disorders to the current list of high-cost, low-probability services that SNFs can bill for outside of the per diem payment. The currently excluded services – chemotherapy and its administration, radioisotopes, and prosthetic devices – are billable separately under Part B. With the passage of this bill, treatments for hemophilia and related bleeding disorders will be added to this list of categorically excluded services and paid for separately under Part B in a budget neutral manner.

Our organizations seek to ensure that all individuals with bleeding disorders can access care in the most medically appropriate setting, including SNFs. Thank you for your leadership on this critical issue. We look forward to working with you and your staff to pass this vital legislation and improve access to care for the patient community we serve.

Sincerely,

The Coalition for Hemophilia B  
Committee of Ten Thousand  
Hemophilia Alliance  
Hemophilia Federation of America  
National Hemophilia Foundation