



NATIONAL HEMOPHILIA FOUNDATION

www.hemophilia.org

June 22, 2015

The Honorable Orrin Hatch (R-UT)
Chairman
Committee on Finance
United States Senate
Washington, DC 20510

The Honorable Ron Wyden (D-OR)
Ranking Member
Committee on Finance
United States Senate
Washington, DC 20510

The Honorable Johnny Isakson (R-GA)
Committee on Finance
United States Senate
Washington, DC 20510

The Honorable Mark R. Warner (D-VA)
Committee on Finance
United States Senate
Washington, DC 20510

Re: Senate Committee on Finance Chronic Care Working Group

Dear Chairman Hatch, Ranking Member Wyden, Senator Isakson, and Senator Warner:

The National Hemophilia Foundation (NHF) is the nation's oldest and largest advocacy organization for people with hemophilia and other inheritable bleeding disorders. NHF is dedicated to ensuring that those affected with bleeding disorders have access to high quality medical care regardless of financial circumstances, place of residence or other factors. We commend the work of the Senate Committee on Finance to focus on Medicare beneficiaries with chronic conditions, and appreciate the opportunity to offer ideas for enhancing care for Medicare beneficiaries with hemophilia and other bleeding disorders.

About Hemophilia and Other Bleeding Disorders

Hemophilia is a rare, chronic bleeding disorder affecting approximately 20,000 people in the US. There are also similar bleeding disorders, like von Willebrand Disease, that affect an estimated 1 million Americans. People with bleeding disorders experience prolonged and spontaneous internal bleeding in the joints and surrounding tissues, increasing the need for surgery due to severe joint damage. Additionally, as a result of treatment with contaminated blood products in the 1980's, many individuals are infected with HIV/AIDS and hepatitis.

People with bleeding disorders infuse clotting factor therapies to replace missing or deficient proteins, which stop or prevent bleeding. These products are more effective and safer than ever, but are extremely expensive. Drug costs for a person with severe hemophilia can be \$250,000 a year or more. Developing an inhibitor (an immune response to treatment), complications such as HIV/AIDS, hepatitis and joint disease, or bleeding as a result of trauma or surgery can increase those costs to \$1 million.

Most individuals with bleeding disorders receive care at hemophilia treatment centers (HTCs), which are centers of excellence that provide comprehensive, multi-disciplinary, patient-centered care for bleeding disorders and their complications. Studies have shown that mortality and hospitalization rates are 40% lower for people who use HTCs than in those who do not, despite the fact that more severely affected patients are more likely to be seen in HTCs. The number of HTCs in a given state varies, with a few

having two or more and some states having none. This means that an individual patient might have to drive several hours to visit their HTC.

Patients are taught to self-infuse by their HTCs because bleeding episodes must be treated immediately; any delay longer than 1-2 hours can cause permanent, irreparable damage to the brain, nerves or joints or even be fatal. This is why the standard of care is for clotting factor concentrate to be kept at home for patients to self-infuse especially in an emergency situation. Some individuals may need assistance infusing and this help is typically provided by a family member or nurse, but in some cases, a patient will need to be infused in a physician's office or hospital clinic.

Access to Skilled Nursing Facility Care

People with hemophilia have complications that increase the likelihood of surgery for damaged joints or liver ailments. To help facilitate recovery, while ensuring that complications and comorbidities are adequately managed, a treating physician may refer a patient to a skilled nursing facility (SNF) after being discharged from the hospital. SNFs are the medically appropriate setting because they can provide short-term, intensive, inpatient rehabilitative services and have the medical and nursing expertise to provide a level of care beyond what is available to individuals who are being treated at home.

The problem is that current Medicare reimbursement methodology for SNFs is limiting access to these facilities for patients with hemophilia and other severe bleeding disorders. It is extremely difficult to find a SNF that will care for hemophilia patients due to the significant losses the facility will incur due to clotting factor costs. SNFs are paid a prospectively determined daily rate for all services provided to patients covered under a Medicare Part A SNF stay and costs for a person with hemophilia will far exceed this per diem payment rate. Clotting factor costs alone following a surgery can exceed \$10,000 per day.

If a SNF is unavailable, other options for patients include inpatient rehabilitation facilities, but many patients are not strong or healthy enough to meet admission requirements; keeping the patient in the acute inpatient setting longer than needed, which increases costs; or sending the patient home. None of these options allow for the level of coordinated, skilled care necessary for a successful recovery.

The size of the affected population is small – fewer than 1100 individuals with hemophilia were on Medicare in 2009 according to the CDC's most recent data, and fewer still need access to SNF services each year – but the inability to access SNF services increases health care costs overall and can even harm patient health.

The Medicare SNF statute allows for certain costly, highly specialized services that SNFs do not typically provide to be billed separately under Medicare Part B, including chemotherapy, radioisotopes, certain types of prosthetics and EPO for dialysis patients. **NHF respectfully requests that the Committee add clotting factor therapies to the list of services that can be billed separately under Medicare Part B for patients with hemophilia during a Medicare Part A SNF stay.** The provision of clotting factor to patients is comparable to the other services where Medicare recognizes the need for separate treatment. Separate payment for clotting factor can be implemented in a budget neutral manner.

Part D Beneficiary Appeals Fairness Act

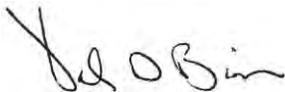
Finally, NHF has also endorsed S. 1488, the Part D Beneficiary Appeals Fairness Act, which is necessary to ensure that people can access treatments. This is important to people with bleeding disorders because increasingly, treatments for complications and co-morbidities like hepatitis and HIV appear on specialty tiers, which require patients to pay exorbitant cost-sharing to access their medications.

This critical legislation would allow Medicare beneficiaries to appeal for a “tiering exemption” giving them a lower cost-share for drugs in the specialty tier, similar to beneficiaries with prescriptions classified on other tiers who have the right to appeal for an exemption allowing them to pay less to access their drug. For this reason, **we urge the Committee to move forward in considering S. 1488**, which will facilitate access to treatment for people with bleeding disorders and will benefit people affected by many other conditions with high-cost treatments.

Conclusion

We hope to ensure that individuals with bleeding disorders have full access to the treatments and care they need to lead healthy, productive lives. NHF appreciates the opportunity to comment on this important new initiative. If you have any questions or would like any additional information, please contact Johanna Gray at jgray@dc-crd.com or 202.484.1100.

Sincerely,

A handwritten signature in black ink that reads "Val Bias". The signature is written in a cursive, slightly slanted style.

Val Bias
Chief Executive Officer
National Hemophilia Foundation