NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

June 6, 2019

The Honorable Richard E. Neal
Chairman
House Ways and Means Committee

The Honorable Kevin Brady
Ranking Member
House Ways and Means Committee

The Honorable Frank Pallone
Chairman
House Committee on Energy and Commerce

The Honorable Greg Walden
Ranking Member
House Committee on Energy and Commerce

Re: *Draft Medicare Part D Legislation*

Dear Chairman Neal, Chairman Pallone, Ranking Member Brady and Ranking Member Walden:

I am writing on behalf of the National Hemophilia Foundation (NHF) in response to your draft Medicare Part D legislation. NHF is the nation's leading advocacy organization working to ensure that individuals affected by hemophilia and related inherited bleeding disorders have timely access to high quality medical care and services, regardless of financial circumstances or place of residence.

Hemophilia is a rare, chronic bleeding disorder affecting approximately 20,000 people in the US. Affected individuals infuse high-cost therapies to replace missing or deficient blood proteins. These therapies are safer and more effective than ever, but are also very expensive. Treatment 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 or more. Similar bleeding disorders, like von Willebrand Disease (VWD), affect up to an estimated 1 million Americans.

While bleeding disorders treatments are covered under Medicare Part B, many Medicare beneficiaries also rely on drugs covered under Medicare Part D to manage their co-morbidities. Due to tainted blood products in the 1980s and 90s, many in our community live with HIV and/or hepatitis C; and others are affected by more common conditions associated with aging have drugs covered under Medicare Part D.

Accordingly, we are very supportive of your efforts to institute an annual out-of-pocket maximum for Medicare Part D. Most beneficiaries have fixed incomes, which makes paying a greater proportion of their income on drug bills very difficult. Therefore, we would encourage you to consider similar policies and institute an out-of-pocket maximum for drugs covered under Medicare Part B. While many patients purchase supplemental coverage to help them cover their costs, people on Medicare due to disability may not be able to purchase supplemental coverage depending on where they live. We support efforts to lower health care costs and make them more predictable for Medicare beneficiaries.

Thank you for considering our comments. If you have any additional questions, or need any additional information, please contact Michelle Rice, NHF Senior Vice President for External Affairs, at mrice@hemophilia.org.

Sincerely,

Val Bias
Chief Executive Officer
National Hemophilia Foundation