NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

March 1, 2021

The Honorable Rachel Prusak
Chair, House Committee on Health Care

RE: Support for HB 2517

Dear Chair Prusak and members of the House Committee on Health Care,

The National Hemophilia Foundation would like to include this letter of support for HB 2517 in the public hearing record.

NHF is the nation's leading advocacy organization for individuals with bleeding disorders. Our mission is to ensure that individuals affected by hemophilia and other inherited bleeding disorders have timely access to quality medical care, therapies, and services, regardless of financial circumstances or place of residence.

NHF strongly supports HB 2517 because it would provide important patient protections and guardrails on step therapy. Passage of this bill would ensure health care providers may override a health plan's step therapy protocols in certain circumstances when it is medically appropriate for a patient.

Step therapy requires a patient to try and fail first on other medications before receiving their doctor-prescribed medication. The practice has become increasingly prevalent and often results in individuals with chronic and progressive conditions having to suffer lengthy delays in accessing the right treatment. For persons with bleeding disorders delay in receiving life-saving medication could be debilitating or even fatal.

NHF recognizes that the complexities involved in treating hemophilia and related bleeding disorders can result in high medical expenses for patients and their health insurance plans. While we appreciate the need for payers to utilize cost containment strategies, it is critical that such strategies not compromise continuity of care for those with complex medical conditions.

Hemophilia and related bleeding disorders are rare, complex genetic conditions for which there are no known cures. Individuals often experience spontaneous and prolonged internal bleeding into the joints and soft tissues. To effectively manage these disorders, patients often depend on ongoing therapy with prescription medications (clotting factor or novel, non-factor treatments) to treat or avoid debilitating and life-threatening internal bleeding episodes that

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can lead to advanced medical issues. While today's therapies are safer and more effective than ever, they are also undeniably costly. For example, the average annual cost of treatment for a person with hemophilia is $250,000 per year.

Clotting factor and non-factor replacement therapies are biological products either derived from human blood plasma or else produced by using recombinant technology; there are no generic equivalents. Differences among these therapies mean that they are neither pharmacologically nor therapeutically equivalent. Collectively, these characteristics make an individual's response and tolerability for a specific product unique.

For these reasons, NHF's Medical and Scientific Advisory Council (MASAC) recommends that individuals retain access to the full range of FDA-approved clotting factor products. Limiting access through utilization management practices like step therapy/fail first could have a negative impact on patient care and ultimately result in higher drug spends. Therefore, drug benefit designs employing these methods should be avoided, and the choice of product used by an individual should remain a decision between patient and physician.

On behalf of individuals in the State of Oregon affected by bleeding disorders, we urge you to support HB 2517 and pass it favorably from committee.

Thank you for considering our comments and making them part of the record. If you have any additional questions, or need any additional information, please contact Nathan Schaefer, NHF Vice President for Public Policy (nschaefer@hemophilia.org).

Sincerely,

Nathan M. Schaefer

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