NATIONAL BLEEDING DISORDERS FOUNDATION
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NEHA
NEW ENGLAND HEMOPHILIA ASSOCIATION

March 11, 2026

The Honorable Members of the House Committee on Healthcare
Rep. William J. Lippert, Jr - Chair
Vermont State House
115 State Street
Montpelier, VT 05633

Re: Opposition to H. 585 – Elimination of Vermont Prescription Drug Out-of-Pocket Maximum

On behalf of the National Bleeding Disorders Foundation and the New England Hemophilia Association, we write to express our opposition to H. 585 (McCoy/Faun). The New England Hemophilia Association (NEHA) and the New England Bleeding Disorders Advocacy Coalition (NEBDAC) provide education and advocacy about bleeding disorders in all six New England states. The National Bleeding Disorders Foundation (NBDF) is a national non-profit organization that represents individuals affected by bleeding disorders across the United States. Our mission is to ensure that individuals affected by hemophilia and other inheritable bleeding disorders have timely access to quality medical care, therapies, and services, regardless of financial circumstances or place of residence.

We recognize that the complexities involved in treating hemophilia and related bleeding disorders can result in high medical expenses. We also understand that state's and insurers need to identify cost containment strategies; however, it is critical that such strategies not compromise continuity of care for those with complex medical conditions. Hemophilia, vonWillebrand's Disease and additional 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 require life-long infusions or injections to prevent debilitating and life-threatening internal bleeding, which can result in frequent hospital stays, or even death.

While we understand and appreciate efforts to address rising health care costs, particularly on the state-level, we believe that H. 585 includes provisions that would undermine the stability of Vermont's insurance market, and jeopardize access to essential care and services for patients with chronic, high-cost conditions like bleeding disorders. We also have severe concerns regarding the bill's expansion of association health plans (AHPs) and short-term, limited-duration insurance (STLDI). While these changes may provide short-term affordability for health individuals, we fear that this is at the expense of individuals who require robust, ongoing coverage.

Expansion of AHPs (Secs. 7-8) allow for associations to offer plans that bypass key Affordable Care Act (ACA) protections, including guaranteed coverage for pre-existing conditions and essential health benefits (EHB's). Bleeding disorders require continuous comprehensive care at Hemophilia Treatment Centers (HTC's), such as the HTC at the University of Vermont in Burlington, infusions, monitoring and preventive treatments that are not optional. AHPs have historically led towards risk segmentation, eroding the risk pool making comprehensive insurance unaffordable for those who need it most. We particularly fear that in a market the size of Vermont's, this could destabilize coverage options. Similarly, authorizing STLDI plans for up to 12 months (Sec. 9) promotes insurance coverage that excludes pre-existing conditions, prescription drugs and hospitalization, in which bleeding disorders patients require for bleeds and joint damage. STLDI increases uninsurance rates and drives-up costs in ACA-compliant plans by taking low-risk enrollees.

Additionally, allowing limited age rating (Sec. 6), even with a five percent deviation cap, deviates from Vermont's commitment to community rating and could disproportionately burden older patients and families with bleeding disorders. Many

Vermonters with bleeding disorders have fought hard for protections that ensure equitable access to care, protections in which this legislature has championed, such as co-pay accumulator adjuster reforms. We urge the Committee to reject H. 585 in its current form to preserve strong consumer safeguards. We work throughout many states on this issue with solutions such as strengthening reinsurance programs and PBM reform, we hope that you view us as a resource in this same regard.

If you would like additional information or have questions, please do not hesitate to contact us at mdelaney@bleeding.org and rpezzillo@newenglandhemophilia.org. Thank you for your consideration of our request.

Sincerely,

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