



January 23, 2025

North Dakota House Industry, Business, and Labor Committee

RE: Committee Hearing on HB 1413

Dear Chairman Warrey and members of the Committee,

The National Bleeding Disorders Foundation (NBDF) is a national non-profit organization that represents individuals with bleeding disorders across the United States. 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. Please accept these comments in support of HB 1216 for the hearing record.

About Bleeding Disorders

Hemophilia is a rare, genetic bleeding disorder affecting about 20,000 Americans that impairs the ability of blood to clot properly. Without treatment, people with hemophilia bleed internally, sometimes due to trauma, but other times simply as a result of everyday activities. This bleeding can lead to severe joint damage and permanent disability, or even – with respect to bleeds in the head, throat, or abdomen – death. Related conditions include von Willebrand disease (VWD), another inherited bleeding disorder, which is estimated to affect more than three million Americans.

Patients with bleeding disorders have complex, lifelong medical needs. They depend on prescription medications (clotting factor or other new treatments) to treat or avoid painful bleeding episodes that can lead to advanced medical problems. Current treatment and care are highly effective and allow individuals to lead healthy and productive lives. However, this treatment is also extremely expensive, costing anywhere from \$250,000 to \$1 million or more annually, depending on the severity of the disorder and whether complications such as an inhibitor are present.



Importance of Financial Assistance to Patients

Many individuals with bleeding disorders rely on patient assistance programs to ensure access to their life-saving specialty drugs. And because patients with bleeding disorders require ongoing medication therapy for the course of their lifetimes, many such patients face the prospect of hitting their out-of-pocket maximum each and every year (in 2026, this will be \$10,150 for an individual, or \$20,300 for a family).¹ Copayment assistance programs play an essential role in mitigating this weighty financial burden – and allow patients to remain adherent to their prescribed treatment regimen, preserving their long-term health and thereby avoiding medical complications that could increase their overall health care spending.

Patients with bleeding disorders cannot select alternative treatments: no generic drugs exist for hemophilia or related conditions. The vast majority of copayment assistance programs are for drugs without generic alternatives. A recent University of Southern California Schaeffer Center analysis found that 71 out of 90 high-expenditure brand drugs that offered coupons had no generic equivalent. The analysis concludes, “these results suggest that most copay coupons are not affecting generic substitution, and many may help patients afford therapies without good alternatives. As such, the copay coupon landscape seems more nuanced, and proposals to restrict coupons should ensure that patients who currently rely on them are not harmed.”²

In addition, all manufacturers of hemophilia specialty biologics offer copayment assistance programs; as a result, assistance for these products does not influence patients to use one product over another. To use the U.S. Department of Health and Human Services’ own formulation from the federal 2021 Notice of Benefit Payment and Parameters (NBPP), hemophilia copay assistance programs do not “disincentivize a lower cost alternative” nor do they “distort the market.”³

Copay Accumulator Adjustment Programs

Copay accumulator adjustment programs (CAAP) limit the utility of copayment assistance programs to consumers, by excluding the financial assistance from the calculation of a person’s deductible and annual out-of-pocket maximum.

Consumers have little choice when it comes to evaluating health plans in advance for the existence of a CAAP. There is a distressing lack of transparency around plan implementation of CAAPs. Typically, language allowing a plan to implement a CAAP is buried deep in the contract, which can be difficult or impossible to find if you only have access to the marketing



materials on a health plan's web site. Manufacturers also are typically unaware of whether a patient's health plan has adopted an accumulator adjustment program. Moreover, individuals covered by a self-funded large group plan may find that their plan changes its policy on copay assistance midway through the plan year (this is problematic in its own right; it would also be unknown to the manufacturer).

Conclusion

The use of CAAPs dramatically increases patient out-of-pocket costs and threatens adherence to treatment for vulnerable individuals affected by serious health conditions. People who live with chronic conditions like bleeding disorders rely on access to quality care, and to accessible and affordable coverage to pay for that care. CAAPs place those patients at risk of being unable to pay for their life saving medication. HB 1216 places necessary and appropriate restrictions on the use of CAAPs by requiring insurers to count all contributions by or on behalf of an insured individual toward their annual cost-sharing requirement.

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, NBDF Senior Vice President for Public Policy and Access (nschaefer@bleeding.org).

Sincerely,

Nathan Schaefer

¹ Since bleeding disorders are genetic conditions, there are many families that include more than one affected individual. These families may thus be subject to the family OOP maximum year after year – an unsustainable financial burden for almost any family. See, e.g., Jake Zuckerman, "A New Battle Between Insurers and Big Pharma is Costing Sick People Thousands," Ohio Capital Journal (Feb. 13, 2020), <https://ohiocapitaljournal.com/2020/02/13/a-new-battle-between-insurers-and-big-pharma-is-costing-sick-people-thousands/>.

² Van Nuys, et al. "A Perspective on Prescription Drug Copayment Coupons." USC Leonard D. Schaeffer Center for Health Policy and Economics (emphasis added), February 2018. Available online at: https://healthpolicy.usc.edu/wp-content/uploads/2018/02/2018.02_Prescription20Copay20Coupons20White20Paper_Final-2.pdf.

³ 84 Fed. Reg. 17545.