



April 10, 2024

Vermont Senate Committee on Health & Welfare
Vermont State House, Room 45
155 State Street
Montpelier, Vermont 05633

Sen. Ginny Lyons
Chair – Senate Committee on Health & Welfare
155 State Street
Montpelier, Vermont 05633

RE: Support House Bill 233 to Protect Copay Assistance for Patients

Dear Chairwoman Lyons and members of the Committee,

The National Bleeding Disorders Foundation (NBDF) is a national non-profit organization that represents 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. The New England Hemophilia Association (NEHA) supports advocacy, education and awareness efforts that build and sustain community among all people impacted by bleeding disorders across Vermont and New England. Please accept this testimony in support of HB 233 for the record as the Committee considers this legislation.

About Bleeding Disorders

Hemophilia is a rare, genetic bleeding disorder affecting about 30,000 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 Copay Assistance to Patients

Many individuals with bleeding disorders rely on copay 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.¹ For health plans being offered on the Marketplace in 2024, out-

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/>.

of-pocket maximums can reach up to \$9,100 for an individual, or \$18,200 for a family.² Copay 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. In fact, data shows that for all commercial market claims for specialty medications where copay assistance was used, only 3.4% of those claims were for a product that may have a generic alternative available.³ A recent University of Southern California Schaeffer Center analysis found that 71 out of 90 high-cost brand name drugs where copay assistance was available 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.”⁴

In addition, all manufacturers of hemophilia specialty biologics offer copay assistance programs; as a result, copay assistance programs for these products do 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.”⁵

Copay Accumulator Adjustment Programs

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

Consumers have little choice when it comes to evaluating health plans in advance for the existence of a CAAP, and in the State of Vermont, half of state marketplace health insurers contain copay accumulator adjuster language.⁶ 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 mid-way through the plan year (this is problematic in its own right; it would also be unknown to the manufacturer).

² Out-of-pocket maximum/limit - glossary (no date) Glossary | HealthCare.gov. US Department of Health and Human Services (HHS) . Available at: <https://www.healthcare.gov/glossary/out-of-pocket-maximum-limit/> (Accessed: November 28, 2022).

³ Evaluation of Co-Pay Card Utilization. IQVIA. Available at: <https://www.iqvia.com/locations/united-states/library/fact-sheets/evaluation-of-co-pay-card-utilization> (Accessed: November 28, 2022).

⁴ 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.

⁵ 3 84 Fed. Reg. 17545.

⁶ Hangst et al. “Discriminatory Copay Policies Undermine Coverage for People with Chronic Illness” AIDS Institute, January 2022. Available online at: www.aidsinstitute.net/documents/final_TAI-2022-Report-Update_021222

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 233 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, and it is our hope that Vermont becomes the 21st U.S. State to ban these practices. 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, nschaefer@hemophilia.org and Richard Pezzillo, Executive Director of the New England Hemophilia Foundation at rpezzillo@newenglandhemophilia.org.

Sincerely,



Nathan Schaefer, MSW
Senior Vice President, Public Policy & Access
National Bleeding Disorders Foundation



Richard Pezzillo
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