



February 9, 2024

Rep. Rob Nosse, Chair
Committee on Behavioral Health and Health Care
Oregon State Capitol
Salem, OR 97301

RE: Support H.B. 4113 to protect patients from harmful “copay accumulator adjusters”

Dear Chairman Nosse,

The Hemophilia Federation of America (HFA) urges your committee to support pending legislation (H.B. 4113) that would protect patients by requiring health insurers to credit all sums paid by or on behalf of patients toward patient deductibles and out-of-pocket (OOP) maximums.

Who We Are

HFA is a non-profit organization representing individuals with bleeding disorders nationwide. Our mission is to ensure that persons with inherited bleeding disorders such as hemophilia have timely access to quality medical care, therapies, and services, regardless of their financial circumstances or place of residence.

We are part of the national All-Copays Count Coalition that was formed to protect consumer access to life-saving therapies and ensure all copays are properly counted towards consumer OOP costs.

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, another inherited bleeding disorder, which affects 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 issues. Current treatment and care are highly effective and allow individuals to lead healthy and productive lives. However, it is also extremely expensive, costing anywhere from \$300,000-\$1 million or more annually, depending on the severity of the disorder and whether complications such as an inhibitor are present.

As a result, people with bleeding disorders rely on comprehensive and uninterrupted health coverage to afford the treatment they require. But *having* coverage, alone, is not enough: recent trends in plan design mean that even with insurance, patients face ever-growing deductibles and OOP maximums. Consequently, many in the bleeding disorders community rely on patient copay assistance programs to help defray the cost-sharing associated with their life-saving medications.

What Are Copay Accumulators

Copay accumulator adjusters are a new cost-containment technique that proliferated in the last few years and are currently found in most commercial health plans. Accumulators can be hard to spot, since they are embedded in long, dense plan documents under many deceptive names (such as “out-of-pocket protection programs” or “specialty copay solutions”). Their impact, however, is unmistakable. Insurers that build accumulators into their health plans *accept* third-party assistance for a subscriber’s cost-sharing obligations (from manufacturers or non-profit organizations), but then refuse to *credit* that assistance to the subscriber’s annual deductible or OOP maximum limit (often with little or no advance notice to the subscriber).

Accumulator programs are exceptionally harmful for persons with high-cost conditions like hemophilia because they can force patients to pay their entire OOP maximum early in the calendar year with one of their first prescription fills. Very few individuals can pay \$9,450 up-front (double for families) to receive their monthly shipment of medication that they rely on to prevent or treat bleeding episodes that could otherwise lead to severe joint damage or even death. Patients confronted with such costs either discontinue their regular treatment or possibly turn to the ER for acute care, resulting in far higher costs for both patients and insurers.

Health plans claim accumulators are needed to prevent third-party copay assistance from artificially inflating drug prices by incentivizing consumers to purchase costlier brand-name products. However, this argument does not apply for those with hemophilia or the many other conditions where no generic alternative is available.

Furthermore, this argument is contradicted by the fact that plans are not simply refusing to accept third-party copay assistance. Instead, **health plans pocket the assistance** – and then “double-dip” by *again* collecting the full cost-sharing amount from the subscriber. In addition, we understand that health plans may not always apply accumulators uniformly, but rather discriminatorily target only those with high-cost conditions like hemophilia.

Nearly all plans in Oregon’s individual market currently apply copay accumulators (including Regence BCBS). The experience of our community members enrolled in these plans has shown that they are not applying accumulators in an effort to curb drug prices but rather to force the costliest subscribers off their plans.

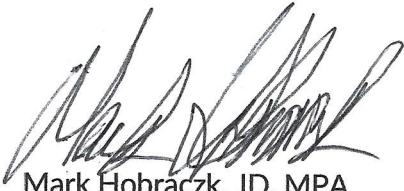
As a result, we strongly urge lawmakers to follow the lead of 19 states (including Washington) that have already acted to restrict copay accumulators. There was broad bipartisan consensus in these states that denying those with the highest-cost conditions the literal lifeline provided by copay assistance is grossly harmful, unfair, and counter-productive. Furthermore, recent research by The AIDS Institute documented that copay accumulator protections did not appreciably increase premiums in the states that enacted them¹.

Given the significant numbers of Medicaid enrollees losing coverage during the “unwinding” of the COVID-19 public health emergency, it is especially critical at this time that persons with life-threatening conditions be able to find adequate coverage alternatives in the ACA Marketplace or other commercial insurance. Therefore, we urge your committee to pass H.B. 4113 so patients can fully access the lifeline that copay assistance provides.

¹ See <https://aidsinstitute.net/documents/TAI-Report-Copay-Accumulator-Adjustment-Programs-2023.pdf>.

Please feel free to reach out to HFA with any questions or for additional information regarding copay accumulator protections.

Sincerely,

A handwritten signature in black ink, appearing to read 'Mark Hobrączk', with a stylized flourish at the end.

Mark Hobrączk, JD, MPA
Senior Manager for Policy
m.hobraczk@hemophiliafed.org