Hemophilia Federation of America™

February 22, 2021

Senator Deb Patterson , Chair
Senate Committee on Health Care
Oregon State Capitol
Salem, OR 97301

RE: Support S.B. 560 to protect patients from harmful "copay accumulator adjusters"

Dear Chairwoman Patterson,

The Hemophilia Federation of America (HFA) urges your committee to support pending legislation (S.B. 560) 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 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 out-of-pocket (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 (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 issues. 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.

As a result, people with bleeding disorders rely on comprehensive and uninterrupted health coverage in order 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. As a result, 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 have 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 subscribers to pay their entire OOP maximum early in the calendar year with one of their first prescription fills. Very few individuals can pay $8,550 up-front (or $17,100 for families) in order 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 may decide they have to discontinue their regular treatment, or possibly turn to the ER for acute care, resulting in far higher treatment costs in both the near- and long-term future.

Health plans claim that accumulators are needed to prevent third-party assistance from artificially inflating drug prices by incentivizing consumers to purchase costlier brand-name products. However, this argument makes no sense 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 assistance. Instead, health plans pocket the third-party 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's 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 Oregon lawmakers to follow the lead of five states (Arizona, Georgia, Illinois, Virginia, and West Virginia) as well as Puerto Rico, which 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 third-party OOP assistance is grossly harmful, unfair and counterproductive. Furthermore, recent research by The AIDS Institute documented that protections against copay accumulators did not appreciably increase premiums in either Arizona or Virginia. See http://www.theaidsinstitute.org/federal-policy/copay-accumulators-and-insurance-issues.

Given the significant cuts to state health programs expected to result from the ongoing coronavirus pandemic, it is critical that persons with life-threatening conditions be able to maintain commercial health coverage for their critical treatment. Therefore, we urge your committee to pass S.B. 560 so that patients are able to fully access the cost-sharing assistance available to them.

Sincerely,

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