May 5, 2026

Mr. Vince Haley
Director
White House Domestic Policy Council

Dr. Casey Mulligan
Affordability Czar
US Department of Health and Human Services

Re: The Costs of PBM Copay Diversion Practices and AFP Abuses – May 2026

Dear Mr. Haley and Dr. Mulligan,

The undersigned represent Americans across the country who are harmed by abusive cost-shifting practices in health insurance. We write to urge the Administration to build on President Trump's commitment to lowering costs for everyday Americans by reining in these practices. We believe the Administration has **existing authority** to curb these abuses and to dismantle the cost and access barriers that stand in the way of millions of Americans who are simply trying to get or stay healthy.

Industry practices are exacerbating affordability and access problems for vulnerable Americans. In recent years, a variety of entities – health insurers, pharmacy benefit managers, and other middlemen – have exploited deficiencies in the Affordable Care Act to shift an increasing share of prescription drug costs to patients and charities. Health plans, PBMs, and other payor-related stakeholders have manipulated the legal definitions of "cost-sharing" and "essential health benefits" so as to shirk plans' obligations to pay for vital medications. In so doing, these entities are putting their own profits above the health and financial security of ordinary Americans – while exposing employers and employer health plans to legal and reputational risks.

- Plans and PBMs have deployed benefit designs ("copay accumulator adjusters") that redirect the value of copay assistance programs **from** patients with serious conditions – cancer, multiple sclerosis, hemophilia, and more – **to** the plans' or PBMs' coffers. Patients, faced with steep and often unexpected bills for their prescription refills, commonly have no choice but to abandon their prescriptions and suffer the grim health consequences of discontinuing treatment.

- Plans and PBMs have invented a new category of "covered non-essential health benefits" (non-EHBs) and applied that designation to targeted medicines. The "non-essential" label in no way reflects the medical value of the drugs at issue; instead, it allows the plan/PBM to set patient copays far above the legal cost-sharing limits that exist to protect patients against crushing cost burdens. Patients who rely on "non-EHB" designated medications **covered** by their plan are required to enroll in the plan's/PBM's cost-shifting program. That program enrolls the patient in copay assistance and then extracts the full amount of that assistance **for the benefit of the plan/PBM.** If the patient refuses to participate in this arrangement, they are forced to pay potentially the full cost of the drug in order to gain access to their medication. Plans and PBMs again line their pockets while patients cope with confusing processes, red tape, and delayed care.

- The latest twist involves a vague new category known as alternative funding programs, or AFPs. AFPs are designed and run by for-profit middlemen or vendors who pitch employers on schemes to secure "alternative sourcing" for specialty drugs used by plan enrollees. AFPs try to strong-arm patients into enrolling in drug manufacturer charitable patient assistance programs (PAPs) that are intended to provide free products to eligible, uninsured individuals for limited periods of time; or they make the patients get their medication from unknown, non-compliant overseas importation programs. In so doing, AFPs deny hardworking employees (who pay good money for their coverage) the benefits of that coverage. Employees and patients experience multiple harms: significant red tape delays (weeks or months), or outright denials of prescribed medication, resulting in dangerous gaps in treatment; lack of access to necessary ancillaries such as needles and syringes; exposure to illegally imported drugs; and/or dissemination of patients' personal health information to third parties.

The Administration has tools to address these abusive practices and ease cost burdens. President Trump has launched multiple initiatives aimed at lowering healthcare costs. We urge the Administration to use its existing enforcement and regulatory authority to curb the abusive practices outlined above that hurt working people and their family members by targeting specialty medications that they rely on to improve and live their lives.

We have some examples and some ideas of how you can address these issues:

- We thank the Administration for its attention to copay accumulators, maximizers, and AFPs in its recently-published PBM transparency rulemaking. The final rule should, as proposed, require PBMs and PBM affiliates to disclose the use of these manipulative strategies to plan sponsors – but this is only a first step.
- We urge the Administration to issue regulations or guidance revising the (court-vacated)[1] 2021 Notice of Benefit and Payment Parameters that allowed plans to implement copay accumulator adjusters. We also urge the Administration to take enforcement action against plans that continue to apply copay accumulators in violation of the court ruling.
- We urge the Administration to promote efficiency by issuing regulations or guidance extending the tri-agencies' "non-EHB" policies to large group and self-insured plans (thus aligning non-EHB policy across individual, small group, large group, and self-insured plans, as promised by the tri-agencies in 2024).[2]
- We urge the Administration to protect private sector employees by enforcing existing standards that (i) govern the processing of claims and appeals from plan denials, and (ii) prohibit discrimination based on a health factor.

Conclusion

Abusive plan designs, manipulated by profit-seeking middlemen, are creating affordability challenges that make it hard for many Americans to live healthy lives. The practices outlined above increase consumers' out-of-pocket costs and decrease the value of coverage they depend upon for their health needs. Fighting back against these abusive practices is a priority for our organizations. We appreciate the opportunity to provide these comments and would like to meet to discuss a path forward to end these harmful practices and better serve the needs of hard-working employees and

[1] *HIV and Hepatitis Policy Institute, et al. v. United States Department of Health and Human Services et al.*
[2] Department of Labor, Treasury, HHS. 2024 April 2. FAQ about Affordable Care Act Implementation Part 66. Available at https://www.dol.gov/agencies/ebsa/about-ebsa/our-activities/resource-center/faqs/aca-part-66.

their families. Please contact Miriam Goldstein, mgoldstein@artemispolicygroup.com, for any additional information or to schedule a meeting.

Sincerely,

AiArthritis
Aimed Alliance
Alliance for Headache Disorders Advocacy
American Kidney Fund
Arthritis Foundation
Bleeding Disorders Foundation of North Carolina
Cancer*Care*
Coalition of Skin Diseases
Coalition of State Rheumatology Organizations
Connecticut Oncology Association
Crohn's & Colitis Foundation
Dermatology Nurses' Association
Eastern Pennsylvania Bleeding Disorders Foundation
Hemophilia Alliance
Hemophilia Federation of America
HIV+Hepatitis Policy Institute
Hope Charities
ICAN, International Cancer Advocacy Network
Immune Deficiency Foundation
Infusion Access Foundation
Lupus and Allied Diseases Association, Inc.
Lupus Foundation of America
National Association of Chain Drug Stores
National Bleeding Disorders Foundation
National Oncology State Network
Organization for Latino Health Advocacy
The AIDS Institute
The Coalition for Hemophilia B
Triage Cancer
US Hereditary Angioedema Association
Western Pennsylvania Bleeding Disorders Foundation

Cc:

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Special Assistant to the President for Healthcare Policy