



July 14, 2023

The Honorable Charles Schumer (D-NY)
United States Senate
Washington, DC 20510

The Honorable Mitch McConnell (R-KY)
United States Senate
Washington, DC 20510

The Honorable Kevin McCarthy (R-CA)
United States House of Representatives
Washington, DC 20515

The Honorable Hakeem Jeffries (D-NY)
United States House of Representatives
Washington, DC 20515

Dear Majority Leader Schumer, Minority Leader McConnell, Speaker McCarthy, and Democratic Leader Jeffries:

The All Copays Count Coalition (ACCC) comprises more than 80 national patient advocacy and provider organizations representing millions of people living with serious, chronic illnesses and has been leading the fight to hold pharmacy benefit managers (PBMs) and insurers responsible for their policies impeding patient access to lifesaving medication. We urge you to include the Help Ensure Lower Patient Copays Act (HELP Copays Act) in any PBM reform package that comes to a vote this year. This bill provides immediate financial relief to patients with serious, complex, chronic and rare diseases, a necessary component to any PBM reforms that come to the floor.

The HELP Copays Act was created to stop abusive practices of PBMs and health insurers that make it impossible for people living with serious chronic illnesses to afford lifesaving medication, *even when they have insurance*. Over the past decade, health insurance deductibles and cost-sharing (copayments or coinsurance) have increased dramatically. As a result, people who rely on specialty and high-cost prescription drugs to manage their chronic illness often rely on financial assistance from charitable foundations and prescription drug manufacturers to afford their out-of-pocket costs.

Recently, many PBMs and health insurers decided they could keep these financial assistance payments without counting them toward their enrollees' annual deductible and out-of-pocket maximum. They call this a "copay accumulator adjustment policy." As a result, many patients who would otherwise hit their out-of-pocket limit never get the benefit of important financial protections promised by the Affordable Care Act. Instead, insurers continue to charge as if they have not been paid, even when they have received thousands of dollars in payments. *Ultimately, this tactic results in higher profits for PBMs and insurance companies while patients go without necessary medication*. This practice is so egregious that the Federal Employees Health Benefit Plan announced earlier this year that it would not accept any plan that employs it.¹

PBMs and insurers often claim that prohibiting them from implementing copay diversion programs would undermine their ability to negotiate drug prices or to control access to high-cost medications. This is

¹ U.S. Office of Personnel Management, Healthcare & Insurance, Letter Number: 2023-04 *Federal Employees Health Benefits Program Call Letter*, March 1, 2023. <https://www.opm.gov/healthcare-insurance/healthcare/carriers/2023/2023-04.pdf>

simply not true: PBMs and insurers tightly control access to high-cost medications by controlling formulary placement, cost-sharing tiers, and employing utilization management such as prior authorization and step therapy. By the time a person with a chronic illness is in a position to be using copay assistance to help them afford a high-cost medication, they have already exhausted other options and gotten approval from the PBM and/or insurer to fill their doctor's prescription.

In fact, there is no evidence that copay accumulator adjustment policies play any role in reducing health care costs. To date, 19 states, the District of Columbia, and Puerto Rico have enacted legislation prohibiting this harmful practice in individual and small group health plans.² An analysis of health plan premiums in states with these laws shows that the laws did not cause health plan premiums to increase.³

The two-part solution in the HELP Copays Act will eliminate barriers to treatment for some of the most vulnerable Americans—those who live with serious, complex chronic illness—ensuring that they can afford the necessary and often life-saving medications prescribed by their providers. Specifically, the bipartisan HELP Copays Act:

- Requires health plans to count prescription drug copay assistance payments made on behalf of an enrollee toward their annual deductible and out-of-pocket limit.
- Prohibits employer health plans from arbitrarily deeming certain covered drugs as “non-essential” to get around legal protections limiting out-of-pocket costs for people who have health insurance.

Currently, these practices by PBMs undermine coverage for pre-existing conditions, hurt patient access to necessary medications, decrease drug adherence, and even cost our health care system more money. Congress can end these harmful practices and prevent these dangerous health outcomes by including the HELP Copays Act in any PBM reform.

Sincerely,

All Copays Count Coalition Steering Committee

Arthritis Foundation
Cancer Support Community
Immune Deficiency Foundation
National Hemophilia Foundation
National Multiple Sclerosis Society
The AIDS Institute

Supporting Organizations

AIDS Foundation Chicago
Aimed Alliance
Alliance for Headache Disorders Advocacy
Alliance for Patient Access
Alliance for Women's Health and Prevention
ALS Association
American Academy of Ophthalmology
American Kidney Fund

² State health insurance laws only apply to individual, small group, and fully-insured large group health plans. The majority of people with commercial insurance are enrolled in large, self-funded employer health plans subject only to federal law. The states that have enacted laws prohibiting copay accumulator adjustment policies can be found at: <https://allcopayscount.org/state-legislation-against-copay-accumulators/>.

³ The AIDS Institute, [Comparison of Marketplace Average Benchmark Premiums Between States With and Without Copay Accumulator Adjustment Bans](https://aidsinstitute.net/documents/Copay-Assistance-Does-Not-Increase-Premiums-Final.pdf), May 2023. Available at: <https://aidsinstitute.net/documents/Copay-Assistance-Does-Not-Increase-Premiums-Final.pdf>

American Cancer Society Cancer Action Network
American College of Rheumatology
American Medical Association
Arthritis & Osteoporosis treatment center PA
Association for Clinical Oncology
Autoimmune Association
Bleeding Disorders Alliance of North Dakota
Bleeding Disorders Foundation of North Carolina
CancerCare
Center for Housing & Health
Chronic Care Policy Alliance
CLL Society
Coalition of Skin Diseases
Crohn's & Colitis Foundation
Cystic Fibrosis Research Institute
Derma Care Access Network
Dermatology Nurses' Association
Diabetes Leadership Council
Diabetes Patient Advocacy Coalition
Eastern PA Bleeding Disorders Foundation
Epilepsy Foundation
EveryLife Foundation for Rare Diseases
Foundation for Sarcoidosis Research (FSR)
Georgia AIDS Coalition
GO2 for Lung Cancer
Haystack Project
HealthyWomen
Hemophilia Council of California
Hemophilia Federation of America
Hereditary Angioedema Association
HIV Medicine Association
HIV+Hepatitis Policy Institute
Infusion Access Foundation
International Foundation for AiArthritis
International Myeloma Foundation
Little Hercules Foundation
Looms For Lupus
LUNgevity Foundation
Lupus and Allied Diseases Association, Inc.
Lupus Foundation of America
Multiple Sclerosis Association of America
NASTAD
National Consumers League
National Eczema Association
National Infusion Center Association (NICA)
National Organization for Rare Disorders
National Psoriasis Foundation
NCODA
Nevada Chronic Care Collaborative
Ovarian Cancer Research Alliance
Pacific Northwest Bleeding Disorders
Partnership to Advance Cardiovascular Health
Patient Access Network (PAN) Foundation
Pride Action Tank
Pulmonary Hypertension Association
Rheumatology Nurses Society

Society of Dermatology Physician Assistants (SDPA)
Spondylitis Association of America
Susan G. Komen
The Assistance Fund
The Headache and Migraine Policy Forum
Triage Cancer
US Hereditary Angioedema Association
Virginia Hemophilia Foundation
West Virginia Chapter, National Hemophilia Foundation
Western Pennsylvania Bleeding Disorders Foundation