

August 11, 2022

House Speaker Adrienne Jones  
H-101, State House  
100 State Circle  
Annapolis, MD 21401

Senate President Bill Ferguson  
H-107 State House  
100 State Circle  
Annapolis, MD 21401

**RE: Protections Needed to Guard Against High Patient Cost-sharing for Prescription Drugs**

Dear Speaker Jones and Senate President Ferguson:

The undersigned patient, provider, and consumer organizations write to request passage of state legislation to protect patients from a practice being implemented by various health insurance plans, pharmacy benefit managers, and employers that is increasing patient costs for prescription medications. This practice, “copay accumulator adjustment programs,” prevents any copayment assistance available to help patients pay for high-cost drugs from counting towards a member’s deductible or maximum out-of-pocket requirements. Although health plans often use different terminology or slightly variable practices, all pose significant threats to the communities we represent. The federal Notice of Benefit and Payment Parameters (NBPP) for 2021 makes it clear that it is the responsibility of individual states to regulate copay accumulator adjustment programs. Accordingly, this is why 14 states and Puerto Rico have banned copay accumulator adjustment programs. This activity in the states has gained the attention of respected legislative institutions such as the National Conference of State Legislators (NCSL) and the National Council of Insurance Legislators (NCOIL).

Copay accumulator adjustment programs result in patients being left with very high and often insurmountable out-of-pocket expenses to access their necessary medications. They are being used despite insurers and pharmacy benefit managers implementing utilization management (UM) protocols, such as prior authorization and step therapy, to ensure patients attempt lower-cost treatment alternatives first. This means that patients who have abided by and cleared the UM protocols in the plan design then confront the challenge of paying for the high out-of-pocket medications prescribed by their provider. As a result, many patients with chronic and rare diseases depend on copayment assistance to be able to afford their high-cost medications, most of which do not have a generic equivalent.<sup>1</sup> Copay accumulator adjustment programs, coupled with the rise of high deductible health plans (plans with deductibles of at least \$1,400 for an individual), and coinsurance as high as 50%, make it difficult, if not impossible, for patients to adhere to their treatment plan.

There is a direct correlation between patient cost and treatment adherence: as out-of-pocket costs increase, so do prescription abandonment rates. A 2021 survey<sup>2</sup> from the National Hemophilia Foundation, Arthritis Foundation, American Kidney Fund, and the Autoimmune Association, found that nearly half of respondents (46%) say they or someone in their immediate household has not been able to afford their out-of-pocket costs in the past year. Further, 6 in 10 patients and caregivers say they would have extreme difficulty affording their treatments and medications without copay assistance being applied to their out-of-pocket costs. The need for legislation prohibiting copayment accumulator adjustment programs has only been exacerbated during the COVID-19 crisis, when many families have

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<sup>1</sup> <https://www.iqvia.com/locations/united-states/library/fact-sheets/evaluation-of-co-pay-card-utilization>

<sup>2</sup> [NHF - National Patients and Caregivers Survey on Copay Assistance \(Key Findings\).pdf \(hemophilia.org\)](#)

lost a substantial portion of their income and are struggling to pay for basic necessities, including medications.

Amongst the most concerning elements of copayment accumulator adjustment programs is that many have been implemented with little to no notification or explanation to the patient. For those patients that do receive notification or an explanation, the language can be difficult to understand, even for the most seasoned of healthcare experts. Patients, therefore, may not truly understand what is happening until they arrive at the pharmacy to pick up their prescription and find out that they must pay for the full cost of the drug, as the copayment assistance they received did not count towards their deductible. As a result, many patients are forced to walk away without their medication, and an unknown number may be forced to abandon treatment altogether.

One of the challenges facing people with kidney disease, HIV, rheumatoid arthritis, cancer, hemophilia, multiple sclerosis, and other complex or rare diseases is that biologics and other high-cost medications are often the only option for effectively treating these diseases. The vast majority of medications used to treat these diseases are placed on a health insurance plan's highest cost-sharing tier for prescription drugs. In many cases, there is only one, or very few, medications available to treat patients with a chronic or rare condition, and it is highly unlikely that those few medications have generic options. In the absence of copayment assistance, these individuals are often unable to afford their treatment, putting their lives at risk. Affordability and access to these treatments is critical.

In the state of Maryland, legislation has been previously introduced to address the use of copay accumulator adjustment programs that limit access to necessary medications for patients across the state. During the 2020 (HB1360/SB623) and 2021 (HB167/SB290) legislative sessions, these bills, introduced by Senator Joanne Benson and Delegate Pat Young, unfortunately, were unsuccessful, despite being supported by nearly 30 patient and provider organizations. However, legislation is already being considered for introduction during the 2023 legislative session and we urge your support when that comes to fruition, as the need to protect access to medications for all Marylanders remains ever-present.

We are deeply concerned about the issues mentioned above and the risks they pose to many patients with chronic or rare diseases who rely on medications to stay alive or healthy. Together, as one voice, we urge you to ensure patients can maintain access to their medications by passing legislation that allows co-pay assistance to count towards a patient's out-of-pocket obligation.

Thank you in advance for your time and for your consideration of this important issue. Please do not hesitate to contact Jamie Sexton at [jsexton@primaryimmune.org](mailto:jsexton@primaryimmune.org) with any questions or for more information at any time. We look forward to hearing from you soon.

Sincerely,

Jamie Sexton  
Director of State Policy  
Immune Deficiency Foundation

Aimed Alliance  
Allergy & Asthma Network

Alliance for Patient Access  
American Association of Clinical Urologists  
American Cancer Society Cancer Action Network  
American College of Gastroenterology  
Amyloidosis Foundation  
Arthritis Foundation  
Association for Clinical Oncology  
Autoimmune Association  
Baltimore County Medical Association  
Cancer Support Community  
Chronic Care Policy Alliance  
Coalition of State Rheumatology Organizations  
Color of Crohn's and Chronic Illness  
Crohn's & Colitis Foundation  
Epilepsy Foundation  
Hemophilia Federation of America  
HIV+Hepatitis Policy Institute  
Immune Deficiency Foundation  
Infusion Access Foundation (IAF)  
International Foundation for AiArthritis  
Little Hercules Foundation  
Lupus and Allied Diseases Association, Inc.  
Lupus Foundation of America  
Maryland Academy of Family Physicians  
Maryland Chapter, American Academy of Pediatrics  
Maryland Dermatologic Society  
Maryland Psychiatric Society, Inc.  
Maryland/DC Society of Clinical Oncology  
MarylandRARE  
MedChi, The Maryland State Medical Society  
Multiple Sclerosis Association of America  
National Eczema Association  
National Hemophilia Foundation  
National Infusion Center Association (NICA)  
National Multiple Sclerosis Society  
National Psoriasis Foundation  
Pulmonary Hypertension Association  
Spondylitis Association of America  
The AIDS Institute  
The ALS Association  
Washington Psychiatric Society

CC: Maryland Insurance Commissioner Kathleen A. Birrane, Health and Government Operations  
Chairperson Joseline Pena-Melnyk, Finance Committee Chairperson Delores Kelley, Finance Committee  
Vice Chairperson Brian Feldman, Maryland Prescription Drug Affordability Board, Van Mitchell and  
Andrew York