

June 25, 2020

Speaker Brad Wilson  
Senate President Stuart Adams  
Utah State Legislature  
Salt Lake City, UT

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

Dear Speaker Wilson and Senate President Adams:

In light of the recent federal Notice of Benefit and Payment Parameters (NBPP) for 2021, the undersigned patient, provider, and consumer organizations write to request state legislative action to protect patients from a practice being implemented by various health insurance plans, pharmacy benefit managers, and employers. This practice, “copay accumulator adjustment programs,” prevents any copayment assistance available to help patients pay for high cost specialty drugs from counting towards a member’s deductible or maximum out of pocket requirements. Although health plans often use different terminology or practices, all pose significant threats to the communities we represent. The NBPP makes it clear that it is the responsibility of individual states to regulate copay accumulator adjustment programs and we have attached legislation passed by Virginia, West Virginia, Illinois, and Arizona that protects patients from high out of pocket costs.

While copay accumulator adjustment programs are employed by insurers or pharmacy benefit managers attempting to control high drug costs, the result is that patients are left with very high out of pocket expenses for their medications. As a result, many patients with chronic and rare diseases depend on copayment assistance programs to be able to afford their specialty medications. 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%, makes 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 recent study clearly showed that when patient costs hit the \$250 mark, over 70% of new patients walk away from the pharmacy empty handed.<sup>1</sup> The need for legislation prohibiting copayment accumulator adjustment programs has only been exacerbated during the COVID-19 crisis, when many families have lost a substantial portion of their income and are struggling to pay for basic necessities, including medications.

Nearly 27 million people in the U.S. may have lost employer-sponsored insurance due to rampant job losses brought on by the COVID-19 pandemic, leaving many more patients likely to transition to state-regulated health insurance plans.<sup>2</sup> This makes it especially concerning that many copayment accumulator adjustment programs have been implemented with little to no notification or explanation to the member. 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

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<sup>1</sup> IQVIA. May 2019. [Medicine Use and Spending in the US; A Review of 2018 outlook to 2023.](#)

<sup>2</sup> <https://www.kff.org/coronavirus-covid-19/issue-brief/eligibility-for-aca-health-coverage-following-job-loss/>

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 HIV, rheumatoid arthritis, cancer, hemophilia, multiple sclerosis, and other complex or rare diseases is that biologics and other specialty 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 a 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.

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. To that end, we have attached legislation that has passed in Virginia, West Virginia, Illinois, and Arizona to prohibit these programs and protect vulnerable patients. Together, as one voice, we urge you to ensure patients can afford their medications. Please contact Ben Chandhok at [bchandhok@arthritis.org](mailto:bchandhok@arthritis.org) with any questions for more information on this important issue.

Sincerely,

Allergy & Asthma Network  
Alliance for Patient Access  
American Association of Clinical Urologists  
American Autoimmune Related Diseases Association  
American College of Rheumatology  
American Kidney Fund  
American Liver Foundation  
Arthritis Foundation  
Cancer Support Community  
Chronic Disease Coalition  
Coalition of State Rheumatology Organizations  
Crohn's & Colitis Foundation  
Cystic Fibrosis Engagement Network  
Cystic Fibrosis Foundation  
Epilepsy Foundation  
EveryLife Foundation for Rare Diseases  
Fabry Support & Information Group  
GBS|CIDP Foundation International  
Global Healthy Living Foundation  
Hemophilia Federation of America  
HIV+Hepatitis Policy Institute  
Immune Deficiency Foundation  
International Foundation for Autoimmune & Autoinflammatory Arthritis

Lupus and Allied Diseases Association, Inc.  
METAvivor  
Multiple Sclerosis Association of America  
National Hemophilia Foundation  
National Infusion Center Association  
National Multiple Sclerosis Society  
National Organization for Rare Disorders  
National Pancreas Foundation  
National Psoriasis Foundation  
Patient Services Inc.  
Pulmonary Hypertension Association  
Rheumatology Nurses Society  
Spondylitis Association of America  
The AIDS Institute  
U.S. Hereditary Angiodema Association  
U.S. Pain Foundation

CC:

Senator Ron Winterton, Chair, Senate Health and Human Services Committee

Representative Brad Daw, Chair, House Health and Human Services Committee

## CHAPTER 661

An Act to amend and reenact [§ 38.2-4214](#) and [§ 38.2-4319](#) of the Code of Virginia and to amend the Code of Virginia by adding in Article 1 of Chapter 34 of Title 38.2 a section numbered [§ 38.2-3407.20](#), relating to health plans; calculation of enrollee's contribution to out-of-pocket maximum or cost-sharing requirement.

[H 2515]

Approved March 21, 2019

Be it enacted by the General Assembly of Virginia:

1. That [§ 38.2-4214](#) and [§ 38.2-4319](#) of the Code of Virginia are amended and reenacted and that the Code of Virginia is amended by adding in Article 1 of Chapter 34 of Title 38.2 a section numbered [§ 38.2-3407.20](#) as follows:

**[§ 38.2-3407.20](#)**. *Calculation of enrollee's contribution to out-of-pocket maximum or cost-sharing requirement.*

A. As used in this section:

"Carrier" shall have the meaning set forth in [§ 38.2-3407.10](#); however, "carrier" also includes any person required to be licensed under this title that offers or operates a managed care health insurance plan subject to Chapter 58 ([§ 38.2-5800](#) et seq.) or that provides or arranges for the provision of health care services, health plans, networks, or provider panels that are subject to regulation as the business of insurance under this title.

"Cost sharing" means any coinsurance, copayment, or deductible.

"Enrollee" means any person entitled to health care services from a carrier.

"Health care services" means items or services furnished to any individual for the purpose of preventing, alleviating, curing, or healing human illness, injury, or physical disability.

"Health plan" means any individual or group health care plan, subscription contract, evidence of coverage, certificate, health services plan, medical or hospital services plan, accident and sickness insurance policy or certificate, managed care health insurance plan, or other similar certificate, policy, contract, or arrangement, and any endorsement or rider thereto, to cover all or a portion of the cost of persons receiving covered health care services, that is subject to state regulation and that is required to be offered, arranged, or issued in the Commonwealth by a carrier licensed under this title. "Health plan" does not mean (i) coverages issued pursuant to Title XVIII of the Social Security Act, 42 U.S.C. 1395 et seq. (Medicare), Title XIX of the Social Security Act, 42 U.S.C. 1396 et seq. (Medicaid) or Title XXI of the Social Security Act, 42 U.S.C. § 1397aa et seq. (CHIP), 5 U.S.C. 8901 et seq. (federal employees), or 10 U.S.C. 1071 et seq. (TRICARE); or (ii) accident only, credit or disability insurance, long-term care insurance, TRICARE supplement, Medicare supplement, or workers' compensation coverages.

**B. To the extent permitted by federal law and regulation, when calculating an enrollee's overall contribution to any out-of-pocket maximum or any cost-sharing requirement under a health plan, a carrier shall include any amounts paid by the enrollee or paid on behalf of the enrollee by another person.**

C. This section shall apply with respect to health plans that are entered into, amended, extended, or renewed on or after January 1, 2020.

*D. Pursuant to the authority granted by [§ 38.2-223](#), the Commission may promulgate such rules and regulations as it may deem necessary to implement this section.*