

June 25, 2020

Speaker Anthony Rendon
Senate President pro Tempore Toni Atkins
California State Legislature
Sacramento, CA 95814

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

Dear Speaker Rendon and Senate President pro Tempore Atkins:

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.¹ 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.² 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

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

² <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 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 Cancer Society Cancer Action Network
American College of Rheumatology
American GI Forum Education Foundation of Santa Maria, CA
American Kidney Fund
American Liver Foundation
American Urological Association
Arthritis Foundation
BREATHE California of Los Angeles County
California Association of Physician Assistants
California Chronic Care Coalition
California Health Collaborative
California Rheumatology Alliance
California Urological Association
Cancer Support Community
Chronic Disease Coalition
Coalition of State Rheumatology Organizations
Crohn's & Colitis Foundation
Cystic Fibrosis Engagement Network
Cystic Fibrosis Foundation

Emphysema Foundation
Epilepsy Foundation
EveryLife Foundation for Rare Diseases
Fabry Support & Information Group
GBS|CIDP Foundation International
Global Healthy Living Foundation
Hemophilia Council of California
Hemophilia Federation of America
Hemophilia Foundation of Southern California
HIV+Hepatitis Policy Institute
Immune Deficiency Foundation
ICAN, International Cancer Advocacy Network
International Foundation for Autoimmune & Autoinflammatory Arthritis
International Topical Steroid Awareness Network
League of United Latin American Citizens – Santa Maria #3252
Looms For Lupus
Lupus and Allied Diseases Association, Inc.
Medical Oncology Association of Southern California, Inc.
Mental Health America
METAvivor
Multiple Sclerosis Association of America
National Association of Social Workers, California Chapter (NASW-CA)
National Hemophilia Foundation
National Infusion Center Association
National Multiple Sclerosis Society
National Oncology State Network
National Organization for Rare Disorders
National Pancreas Foundation
National Psoriasis Foundation
Neuropathy Action Foundation
Patient Services Inc.
Pulmonary Hypertension Association
Rheumatology Nurses Society
Spondylitis Association of America
Susan G. Komen California
The AIDS Institute
The Myositis Association
U.S. Hereditary Angiodema Association
U.S. Pain Foundation

CC:

Senator Richard Pan, Chair, Senate Committee on Health

Assemblymember Jim Wood, Chair, Assembly Committee on Health

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.