



July 1, 2020

Dear Representative:

Throughout the country, millions of patients rely on cost-sharing assistance programs, which reduce patient out-of-pocket costs for prescription medications. For many individuals, these cost reductions are significant, allowing them to afford the medications necessary to treat acute and chronic conditions. Without reliable access to these medications, patients will face complications and worsened health outcomes.

On behalf of patients we represent, we strongly oppose recent policy changes in the 2021 Notice of Benefit and Payment Parameters (NBPP) that would allow the exclusion of manufacturer cost-sharing assistance from counting towards patients' out-of-pocket maximums in the commercial market. This policy will prevent patients from accessing the medications they depend upon and create unnecessary barriers to maintaining effective treatment plans, especially during the global Covid-19 pandemic.

Therefore, we urge Congress to pass legislation that would delay the implementation of this rule to at least 2022 and reinstate the limitations on copay accumulators included in the 2020 NBPP to ensure co-pay assistance counts for brand name drugs that do not have a generic alternative. This would allow the Centers for Medicare & Medicaid Services (CMS) additional time to gather stakeholder input on the value of cost-sharing assistance and issue guidance limiting copay accumulators. This will protect patients from the negative impact of this rule during the current public health emergency and allow for a more thoughtful and deliberative rulemaking process to occur in 2022.

When a patient's cost-sharing assistance for the year is exhausted because of an accumulator adjustment program, the patient can face thousands of dollars in unexpected costs at the pharmacy. For patients with chronic diseases who rely on multiple medications to maintain health, this unexpected increase in the costs of their medications could cause patients to discontinue treatment. This is unacceptable.

Due to this rule change, it is expected that many commercial and employer-sponsored insurance plans will implement or expand the use of accumulator adjustment programs. The implementation of these programs by insurers and

pharmacy benefit managers (PBMs) has already been on the rise, and this rule will eliminate any remaining barrier to prevent insurers from taking this action.

For even the savviest consumer, health insurance plans are complex and difficult to decipher. Therefore, the addition of these accumulator adjustment programs to beneficiaries' existing plans could easily go unnoticed. This is even more likely when they are given misleading monikers, like co-pay protection programs, as has been seen. Therefore, not only will patients face a significant increase in costs, most will have little advance notice of the change and therefore, will have no opportunity to plan for these increased costs.

Further, patients are facing unprecedented risk and hardship during the ongoing pandemic. Many families are experiencing economic insecurity due to lost jobs and for others care has been disrupted due to the country's ongoing response to the coronavirus. This is the worst possible time to further jeopardize the protections and support on which patients rely.

We greatly appreciate your assistance in safeguarding the care that our patients rely upon and ensuring that access to critical medications and treatments is not interrupted. **Please quickly pass legislation to delay implementation of this policy and protect access to needed treatments.**

Should you have any questions or comments, please contact: Liz Helms, Director, CCPA, lizh@chroniccarealliance.org or Carl Schmid, Executive Director, HIV+Hepatitis Policy Institute, cschmid@hivhep.org. Thank you very much.

Sincerely,

Chronic Care Policy Alliance
HIV+Hepatitis Policy Institute

National Organizations

Aimed Alliance
Allergy & Asthma Network
Alliance for Patient Access
American Association of Clinical Urologists (AACU)
American Autoimmune Related Diseases Association (AARDA)
American Behcet's Disease Association (ABDA)
American Bone Health
American College of Rheumatology
American Kidney Fund
Arthritis Foundation
Association of Women in Rheumatology
Caregiver Action Network

Chronic Disease Coalition
Coalition of State Rheumatology Organizations
Consumers for Quality Care
Cutaneous Lymphoma Foundation
Cystic Fibrosis Research, Inc. (CFRI)
Dermatology Nurses' Association
Diabetes Patient Advocacy Coalition (DPAC)
FORCE: Facing Our Risk of Cancer Empowered
G III Associates, LLC
GLMA: Health Professionals Advancing LGBTQ Equality
Global Healthy Living Foundation
Global Vitiligo Foundation
HealthHIV
HealthyWomen
Hemophilia Federation of America
House of Blahnik
Immune Deficiency Foundation
International Cancer Advocacy Network (ICAN)
International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)
International Myeloma Foundation
International Pemphigus and Pemphigoid Foundation
International Topical Steroid Awareness Network
Kaiser Permanente MDV
LUNGeivity Foundation
Lupus Foundation of America
Men's Health Network
Multiple Sclerosis Association of America
National Alopecia Areata Foundation
National Coalition for LGBT Health
National Diabetes Volunteer Leadership Council
National Eczema Association
National Hemophilia Foundation
National Infusion Center Association
National Minority Quality Forum
Neuropathy Action Foundation
Ovarian Cancer Research Alliance (OCRA)
Patient Access Network (PAN) Foundation
Patients Rising Now
Presbyterian HIV Network, PHEWA, Presbyterian Church USA
Pulmonary Fibrosis Foundation
Pulmonary Hypertension Association

RetireSafe
Scleroderma Foundation
Scleroderma Research Foundation
The AIDS Institute
The Foundation for Sarcoidosis Research
The Hepatitis C Mentor and Support Group, Inc. – HCMSG
The Little Hercules Foundation

State/Local Organizations

Medical Advocacy & Outreach (Alabama)
Axis Advocacy (California)
California Chronic Care Coalition (California)
California Life Sciences Association (CLSA) (California)
HIV + Aging Research Project--Palm Springs (California)
Let's Kick ASS ~ AIDS Survivor Syndrome (California)
LGBT Community Center of the Desert (California)
Looms for Lupus, Inc (California)
Medical Oncology Association of Southern California (MOASC) (California)
California Health Collaborative (California)
Colorado Chronic Care Collaborative (Colorado)
Let's Talk About Change LLC (Colorado)
One Colorado (Colorado)
Anchor Health Initiative (Connecticut)
Optimus Healthcare Inc. (Connecticut)
Delaware HIV Consortium (Delaware)
South Florida Cancer Association (Florida)
The McGregor Clinic, Inc. (Florida)
Hep Free Hawaii (Hawaii)
AIDS Foundation Chicago (Illinois)
Aspire Indiana Health (Indiana)
SLK Health Services (Maryland)
North Shore Alliance of Gay and Lesbian Youth (Massachusetts)
McClees Clinic (Michigan)
Mercy Health (Michigan)
Midwest Children's Resource Center (Minnesota)
BlaqOut, Inc. (Missouri)
SAVE, Inc. (Missouri)
WU Peds ID/Project ARK/The Spot (Missouri)
Midwest Hemophilia Association (Missouri)
Hemostasis and Thrombosis Center of Nevada (Nevada)
Nevada Chronic Care Collaborative (Nevada)

Joan G Lovering Health Center (New Hampshire)
New Jersey Mayors Committee on Life Sciences (New Jersey)
Havas Tonic (New York)
Mount Sinai Institute for Advanced Medicine (New York)
Equality North Carolina (North Carolina)
Mental Health America of Ohio (Ohio)
Ohio Association of Rheumatology (Ohio)
Ohio Bleeding Disorders Council (Ohio)
Ohio Chapter National Association of Pediatric Nurse Practitioners (Ohio)
Ohio State Grange (Ohio)
OHSU Partnership Project (Ohio)
Eastern Oregon Center for Independent Living (Oregon)
HIV Alliance (Oregon)
Foundation for Ichthyosis & Related Skin Types, Inc. (Pennsylvania)
Congreso de Latinos Unidos (Pennsylvania)
Einstein Healthcare Network (Pennsylvania)
North Central District AIDS Coalition, Incorporated (Pennsylvania)
Medical Sciences, University of Puerto Rico (Puerto Rico)
Connect to Protect (Tennessee)
Avita Pharmacy (Texas)
Regarding Cancer (Texas)
Gay City: Seattle's LGBTQ Center (Washington)
Seattle Counseling Service (Washington)
AIDS Task Force of the Upper Ohio Valley (West Virginia)