



The Honorable Xavier Becerra Secretary
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

The Honorable Julie Su
Acting Secretary
U.S. Department of Labor 200
Constitution Avenue NW
Washington, DC 20210

October 6, 2023

Re: U.S. District Court Decision on 2021 Notice of Benefit and Payment Parameters Final Rule

Dear Secretary Becerra and Acting Secretary Su:

The All Copays Count Coalition (ACCC), on behalf of the 86 undersigned organizations, is writing in support of the U.S. District Court for the District of Columbia’s recent decision to vacate the provision of the Trump-era 2021 Notice of Benefits and Payment Parameters (NBPP) allowing commercial market health plans to implement so-called “copay accumulator adjustment policies.” In light of this decision, we urge the Department of Health and Human Services (HHS) to quickly issue guidance clarifying to health insurance issuers that they must follow the copay assistance provision included in the 2020 NBPP; and, further, that they must inform enrollees subject to a copay accumulator adjustment policy of this change. This is particularly urgent as enrollees will soon be reviewing their health plan options and budgeting their healthcare finances for the coming year. We also urge HHS not to appeal this important legal decision.

The high cost of health care – even for people who have health insurance – continues to pose a barrier to care for millions of Americans. A recent KFF poll found that 44% of people with health insurance worry about being able to afford their deductible before their health insurance starts paying for care, and that about half of adults would not be able to afford an unexpected medical bill of \$500.¹ This is exactly the situation in which copay accumulator adjustment policies have left people living with serious, complex, chronic illness. These policies allow insurers and pharmacy benefit managers (PBMs) to pocket copay assistance – intended to help patients who rely on specialty and high-cost brand medications meet their cost-sharing burden – without counting those payments toward the enrollee’s (often substantial) out-of-pocket limit.

¹ Montero A., Kearney A., Hamel L., and Brodie M., July 14, 2022, “Americans Challenges with Health Care Costs” Available at: <https://www.kff.org/health-costs/issue-brief/americans-challenges-with-health-care-costs/>.

The U.S. District Court vacated the provision of the 2021 NBPP that allows this practice. That rule amended a provision of the 2020 NBPP (45 C.F.R. § 156.130(h); version effective from June 24, 2019 to July 12, 2020) that generally required insurers and PBMs to count copay assistance amounts they received on an enrollee's behalf toward that enrollee's annual deductible and out-of-pocket limit.² We urge HHS to quickly inform insurance issuers that they must immediately comply with the 2020 NBPP copay assistance provision (45 C.F.R. § 156.130(h); version effective from June 24, 2019 to July 12, 2020). HHS should further require insurance issuers to notify enrollees of this change and advise them what to expect when they use copay assistance to meet their deductible and cost-sharing requirements. By taking this action, HHS would be upholding the Biden Administration's commitments to making health care more affordable, addressing health care disparities, reducing medical debt, and upholding the patient protections intended by the Affordable Care Act.

We note that the decision in this case remands the issue to HHS to consider whether to revise regulations relating to copay assistance. We urge you to remember that the patients we represent are among those most likely to hit their annual out-of-pocket limit when they get the care they need. While copay assistance may not be the best solution to fill in gaps left by health insurance plans that shift too much of the burden of high health care costs to patients, it is for now the only solution that people living with serious, complex, chronic illness have. As you consider future action, we urge you to ensure that all copay assistance paid on behalf of an enrollee continues to count toward their annual deductible and out-of-pocket limit.

The undersigned members of the ACCC share the same mission: to support the patients we represent through advocacy for adequate access to lifesaving or lifechanging care. We look forward to working with you on these actions to ensure treatment access and affordability for the patient communities we serve.

We respectfully request a meeting with you or the appropriate staff to continue this discussion. Please contact Rachel Klein, Deputy Executive Director of The AIDS Institute, on behalf of the Steering Committee of the All Copays Count Coalition at rklein@tmail.org if you have any further questions.

Sincerely,

Ai arthritis
AIDS Foundation Chicago
Aimed Alliance
Alliance for Headache Disorders Advocacy
Alliance for Patient Access
Alliance for Women's Health and
Prevention
ALS Association
American Cancer Society Cancer Action

Network
Arthritis Foundation
Association for Clinical Oncology
Association of Women in Rheumatology
Autoimmune Association
Biomarker Collaborative
Bleeding Disorders Alliance of North Dakota
Bleeding Disorders Foundation of North
Carolina

² The 2020 NBPP includes an exception allowing copay accumulator adjustment policies when the assistance is received for a medication that has a generic alternative, and the enrollee has not gone through an appeal or exceptions process to gain approval to use the brand drug instead.

Cancer Support Community
CancerCare
Chronic Care Policy Alliance
CLL Society
Coalition of Skin Diseases
Coalition of State Rheumatology
Organizations
Crohn's & Colitis Foundation
Cystic Fibrosis Engagement Network
Cystic Fibrosis Research Institute
Derma Care Access Network
Diabetes Leadership Council
Diabetes Patient Advocacy Coalition
Dravet Syndrome Foundation
Eastern Pennsylvania Bleeding Disorders
Foundation
Epilepsy Foundation
EveryLife Foundation for Rare Diseases
Exon 20 Group
Florida Society of Rheumatology
Georgia AIDS Coalition
GO2 for Lung Cancer
Good Days
Haystack Project
HealthyWomen
Hemophilia Association of the Capital Area
Hemophilia Council of California
Hemophilia Federation of America
HIV+Hepatitis Institute
HIV Medicine Association
ICAN, International Cancer Advocacy
Network
Immune Deficiency Foundation
Infusion Providers Alliance (IPA)
International Myeloma Foundation
Little Hercules Foundation
Looms for Lupus
LUNgevity Foundation
Lupus and Allied Diseases Association, Inc.
Lupus Foundation of America

MET Crusaders
MLD Foundation
Movement Disorders Policy Coalition
National Bleeding Disorders Foundation
National Eczema Association
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Organization of Rheumatology
Management
National Pancreas Foundation
National Psoriasis Foundation
NCODA, Inc.
Nevada Chronic Care Collaborative
New Mexico Society of Clinical Oncology
Ovarian Cancer Research Alliance
Pacific Northwest Bleeding Disorders
Partnership to Advance Cardiovascular
Health
Patient Access Network (PAN) Foundation
PD-L1 Amplifieds
Platelet Disorder Support Association
Project Sleep
Rheumatology Nurses Society
Ryan White Medical Providers Coalition
Society of Dermatology Physician Assistants
(SDPA)
Spondylitis Association of America
Susan G. Komen
The AIDS Institute
The Assistance Fund
The Headache and Migraine Policy Forum
Triage Cancer
US Hereditary Angioedema Association
Virginia Hemophilia Foundation
Vision Health Advocacy Coalition
wAIHA Warriors
Western Pennsylvania Bleeding Disorders
Foundation

CC: Neera Tanden, Chiquita Brooks LaSure, Ellen Montz, Amber Rivers