

December 29, 2020

The Honorable Seema Verma  
Administrator  
Centers for Medicare and Medicaid Services  
U.S. Department of Health and Human Services  
Room 445-G-Hubert H. Humphrey Building  
200 Independence Avenue SW  
Washington, DC 20201

Re: CMS-9914-P; HHS Notice of Benefit and Payment Parameters for 2022 and Pharmacy Benefit Manager Standards; Updates to State Innovation Waiver (Section 1332) Implementing Regulations

Dear Administrator Verma:

The All Copays Count Coalition (ACCC), a network of over 80 chronic and rare disease member organizations representing millions of patients throughout the United States, appreciates this opportunity to comment on the proposed Notice of Benefit & Payment Parameters (NBPP) for 2022. Although the proposal addresses many rules and issuer activities of importance to our constituents, the focus of this letter is the absence of any language or provision addressing limits imposed by payers or PBMs on manufacturers' copay assistance for high-cost pharmaceuticals. We had hoped to see a return to the agency's previous prohibition of most so-called 'copay accumulator programs' in this proposed rule and are disappointed by its absence. Implementation of the 2022 NBPP will further encourage the use of these harmful policies by payers, and with no reasonable alternative or right to appeal for those individuals most directly affected. We urge you to return to the copay accumulator language that was included in the proposed 2020 NBPP that prohibited payers from excluding copay assistance from counting towards patients' cost-sharing, with limited exceptions.

For patients with serious chronic conditions, including life-threatening illnesses, access to medication is essential. Although 63% of Americans are unable to afford even a \$500 emergency expense,<sup>1</sup> individual health care deductibles, which must be paid in their entirety before a plan pays one dollar toward a patient's care, now average \$4,328 annually.<sup>2</sup> Escalating deductibles and out of pocket health costs jeopardize access to care for many patients. For millions of Americans living with complex chronic conditions, the only way to access their specialty medications (many without generic alternatives) is with copay coupons, discount cards, and charitable assistance.

The ACCC supports CMS's previously stated intent to ensure manufacturer assistance fully benefits the patient, a goal which is threatened with the growing prevalence of copay accumulator adjustment programs implemented by pharmacy benefit managers and payers. The 2021 NBPP, finalized in May of this year, grants issuers the discretion not to count manufacturer copay assistance toward a beneficiary's annual cost sharing, regardless of generic availability. Despite our urging reconsideration of

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<sup>1</sup> Bankrate.com

<sup>2</sup> eHealth, '[How much does individual health insurance cost per month?](https://www.ehealthinsurance.com/resources/individual-and-family/how-much-does-individual-health-insurance)', updated November 18, 2019, viewed online July 16, 2020 (<https://www.ehealthinsurance.com/resources/individual-and-family/how-much-does-individual-health-insurance>)

their position prior to finalizing the rule, and despite taking the opposite stance in the 2020 NBPP, HHS proceeded as planned, failing to protect patients amidst a global pandemic.

According to a recent National Hemophilia Foundation (NHF) online [survey](#), more than 80% of American voters – across political parties – believe the government should require copay assistance to count towards patients’ annual out of pocket limits. We urge you to reflect this sentiment in the 2022 NBPP and ensure that copay assistance counts towards a patients’ cost-sharing. Please contact Anna Hyde at [ahyde@arthritis.org](mailto:ahyde@arthritis.org) or 202-843-0105 with any questions or if we can be of assistance.

Sincerely,

Advocacy & Awareness for Immune Disorders Association  
AIMED Alliance  
American Autoimmune and Related Diseases Association  
American Kidney Fund  
APS Foundation of America  
Arthritis Foundation  
Cancer Support Community  
Community Liver Alliance  
Cystic Fibrosis Foundation  
Diabetes Leadership Council  
Diabetes Patient Advocacy Coalition  
Global Healthy Living Foundation  
Haystack Project  
Hemophilia Federation of America  
HIV+HEP Policy Institute  
Immune Deficiency Foundation  
International Foundation for Autoimmune and Autoinflammatory Arthritis  
International Myeloma Foundation  
Lupus and Allied Diseases Association  
Lupus Foundation of America  
MLD Foundation  
Multiple Sclerosis Association of America  
National Hemophilia Foundation  
National Multiple Sclerosis Society  
National Organization for Rare Disorders  
Patient Access Network (PAN) Foundation  
Pulmonary Hypertension Association  
Rheumatology Nurses Society  
Sjogren’s Foundation  
Susan G. Komen  
The AIDS Institute  
The Assistance Fund  
U.S. Hereditary Angioedema Association