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July 17th, 2020

Seema Verma, Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Att: CMS-2842-P
P.O. Box 8016
Baltimore, MD 21244-8016

Re: Pharmacy Benefit Managers Accumulator Programs and their Impact on AMP and Best Price (CMS-2842-P)

Dear Administrator Verma,

The Global Healthy Living Foundation (GHLF) writes to you regarding the proposed revisions to Medicaid, specifically the changes to Pharmacy Benefit Managers (PBM) Accumulator Programs and their impact on Average Manufacturer Price (AMP) and best price.

By way of background, GHLF is a 21-year-old non-profit patient organization reaching millions of chronically ill patients and their caregivers across the country through social media, community events, and online support and education. Our ArthritisPower registry of nearly 30,000 patient participants was developed as part of the National Patient-Centered Clinical Research Network (PCORnet) with data capture mapped to the PCORnet Common Data Model. GHLF works to improve the quality of life for patients living with chronic disease by making sure their voices are heard and advocating for improved access to care at the local and federal level. Our patients suffer from chronic conditions including arthritis, psoriasis, gastrointestinal disease, cardiovascular disease, sickle cell, lung disease, MS, diabetes, migraine and others.

Our patient community is among those that rely on patient assistance programs like copay cards and discount coupons in order to continue to afford the medication that they and their physician have determined is the most effective. As such, they are the ones who are most hurt by the recent growth of copay accumulator adjustors and their continued allowance in health plans. This proposed rule takes things a step farther and forces manufactures to make assumptions about the prevalence of accumulator programs and how much of their assistance programs are going to the patient and how much is going to accumulator programs. Unfortunately, the only way for manufactures to assume that all of the assistance programs are going to the patients, like they currently do, would be in states where accumulator adjustors are banned: Arizona, Illinois, Virginia, and West Virginia.

While we understand that this rule is limited just to how manufactures set their best price within Medicaid negotiations, we are worried that due to the steep penalties that they may face for noncompliance, it could lead them to curtail their assistance programs in the commercial market.

We are steadfastly opposed to anything that could endanger the assistance programs that our patient community relies on to remain medically stable.

Furthermore, we wanted to note that we are troubled by the 30-day comment period given for this rule. This ruling has the potential to negatively impact millions of patients around the country and we were not given the usual allotted time to study the impact of the ruling and fully evaluate our opinions. That this rushed timeline was provided with no explanation for why the usual 60-day period would be cut in half is all the more unsettling. We hope that for future rulings that impact the health care of millions of Americans, we will be given the appropriate amount of time to evaluate and comment.

We do appreciate the opportunity to provide comments on regulatory changes that will have direct impacts on our patient community. Please contact me at snewmark@ghlf.org for more information from the perspective of chronically ill patients, including those with psoriasis, inflammatory bowel disease and autoimmune arthritis or any other chronic conditions.

Respectfully submitted,

A handwritten signature in black ink that reads "Steven Newmark". The signature is written in a cursive, flowing style.

Steven Newmark, JD, MPA
Director of Policy and General Counsel
Global Healthy Living Foundation