



February 10, 2023

The Honorable Earl L. Carter
U.S. House of Representatives
Washington, DC 20515

Rep. Yvette Clarke
U.S. House of Representatives
Washington, DC 20515

Rep. Bonnie Watson Coleman
U.S. House of Representatives
Washington, DC 20515

Rep. Diana DeGette
U.S. House of Representatives
Washington, DC 20515

The Honorable Nanette Barragán
U.S. House of Representatives
Washington, DC 20515

Rep. Brian Fitzpatrick
U.S. House of Representatives
Washington, DC 20515

Re. Mariannette Miller-Meeks
U.S. House of Representatives
Washington, DC 20515

Dear Representatives Carter, Barragán, Clarke, Coleman, DeGette, Fitzpatrick, and Miller-Meeks:

On behalf of the nearly 40,000 children and adults with cystic fibrosis (CF) in the United States, we write to express our support for the Help Ensure Lower Patient Copays Act (HELP Copays Act). Patients with chronic conditions like CF often struggle to afford their care. This legislation addresses two important issues by requiring insurers to apply third party assistance to out-of-pocket maximums and other patient cost-sharing requirements, as well as ensuring any item or service covered by a health plan is considered part of their essential health benefits (EHB) package and thus cost-sharing for these must be counted towards patients' annual cost-sharing limits. The HELP Copays Act would ensure patients' health and financial wellbeing are not sacrificed in the ongoing systemic debate between insurers and pharmaceutical companies about prescription drug pricing.

Cystic fibrosis is a life-threatening genetic disease that causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. Cystic fibrosis is both serious and progressive; lung damage caused by infection is irreversible and can have a lasting impact on length and quality of life. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. While advances in CF care are helping people live longer, healthier lives, we also know that the cost of care is a barrier to care for many people with the disease.

This legislation would ban accumulator programs in federally regulated plans. Accumulator programs prevent third-party payments from counting towards deductibles and out-of-pocket limits and therefore increase out-of-pocket costs for patients—which can cause people with CF to forgo needed care and lead to adverse health outcomes. According to a survey conducted by George Washington University of

over 1,800 people living with CF and their families, nearly half reported delaying or forgoing care—including skipping medication doses, taking less medicine than prescribed, delaying filling a prescription, or skipping a treatment altogether—due to cost concerns.¹ Because CF is a progressive disease, patients who delay or forgo treatment face increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations.

The HELP Copays Act would also require covered benefits to be considered EHBs. Currently, private employer health plans are allowed to deem certain categories of prescription drugs as “non-essential.” This determination allows plans to substantially adjust their cost-sharing for a particular drug or eliminate coverage for certain specialty medications altogether. In doing so, plans can require enrollees to seek free drug from manufacturers or collect the maximum amount of copay assistance available through manufacturer and other third-party programs. These strategies include an accumulator component, which adds to the considerable cost and administrative burdens for people with CF. Cystic fibrosis treatments rarely have lower-cost generic alternatives and, when private employer plans exclude specialty CF medications or cover them while placing significant administrative and financial burden on the enrollee, people with CF face the difficult choice of foregoing these necessary treatments, changing to an often more costly insurance plan from the ACA marketplace, or in some cases seeking alternate employment.

We understand the challenge insurers face in managing the rising cost of drugs, and that copay assistance programs mask bigger cost and affordability issues in the health care system. However, cost containment strategies that further burden patients are unacceptable. The situation has become even more dire as a company that manufactures CF therapies recently reduced the amount of copay assistance available for people enrolled in accumulator programs.

Thank you for your leadership in introducing the HELP Copays Act. The Cystic Fibrosis Foundation appreciates your attention to this important issue for the CF community and we stand ready to work with you to ensure this bi-partisan legislation becomes law.

Sincerely,



Mary B. Dwight
Chief Policy & Advocacy Officer
Senior Vice President, Policy & Advocacy
Cystic Fibrosis Foundation

¹ https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs_policy_briefs