CYSTIC FIBROSIS FOUNDATION®

February 10, 2023

Utah Senate Business and Labor Committee
350 North State, Suite 320
PO Box 145115
Salt Lake City, Utah 84114

Dear Chairman Bramble and Members of the Senate Business and Labor Committee,

On behalf of the over 520 people with cystic fibrosis (CF) in Utah, we write to express our support for SB 184, which would require insurers to apply third-party assistance to out-of-pocket maximums and other patient cost-sharing requirements. It also would ensure that 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. We recognize that copay assistance is problematic; it allows pharmaceutical companies to charge payers high prices, while shielding many individual patients from the costs. It is reasonable that payers would push back against this tactic, as drug costs continue to increase. Nevertheless, patients with chronic diseases like CF often struggle to afford their care and rely on copay assistance to access vital medications. SB 184 would help ensure patients' health and financial wellbeing are not sacrificed in the ongoing, systemic debate between payers and pharmaceutical companies about prescription drug pricing.

Cystic fibrosis is a life-threatening genetic disease that affects nearly 40,000 children and adults in the United States. CF 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.

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.

Accumulator programs also place additional financial strain on people with CF who are already struggling to afford their care. More than 70 percent of survey respondents indicated that paying for health care has caused financial problems such as being contacted by a collection agency, filing for bankruptcy, experiencing difficulty paying for basic living expenses like rent and utilities, or taking a second job to make ends meet. And while three quarters of people received some form of financial

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

assistance in 2019 to pay for their health care, nearly half still reported problems paying for at least one CF medication or service in that same year.

SB 184 would also require covered benefits to be considered EHBs. Currently, private 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 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. Accumulators are especially challenging for a disease like CF, which has no generic options for many of the condition’s vital therapies. The situation has become even more dire as a company that manufacturers CF therapies recently reduced the amount of copay assistance available for people enrolled in accumulator programs.

We urge you to support SB 184 and help ensure continued access to quality, specialty care for people with CF. The Cystic Fibrosis Foundation appreciates your attention to this important issue for the CF community in Utah.

Sincerely,

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