March 29, 2024

Committee on Health
California State Assembly
1020 N Street, Room 390
Sacramento, CA 95814

Dear Honorable Members of the Committee on Health:

On behalf of the more than 2,500 people living with cystic fibrosis (CF) in California, we write to express our support for AB 2180, which would require insurers to apply third-party assistance to out-of-pocket maximums and other patient cost-sharing requirements and require covered benefits to be considered essential health benefits (EHBs). 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. AB 2180 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.

About Cystic Fibrosis
Cystic fibrosis is a progressive, genetic disease that affects the lungs, pancreas, and other organs. There are close to 40,000 children and adults living with cystic fibrosis in the United States, and CF can affect people of every racial and ethnic group. 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 Jeopardize Access to Care
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 skipping medication doses, taking less medicine than prescribed, delaying filling a prescription, or skipping a treatment altogether due to cost concerns.[i] Because CF is a progressive disease, patients who delay or forgo treatment—even for as little as a few days—face increased risk of lung exacerbations, costly hospitalizations and potentially irreversible lung damage.[ii]

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

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.

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 manufactures CF therapies recently reduced the amount of copay assistance available for people enrolled in accumulator programs.

AB 2180 would also require covered benefits to be considered essential health benefits. 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 drugs from manufacturers or collect the maximum amount of copay assistance available through manufacturers and other third-party programs. These strategies include an accumulator component, which adds to the considerable costs and administrative burdens for people with CF. Cystic fibrosis treatments rarely have generic alternatives so 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.

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We urge you to support AB 2180 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 California.

Sincerely,

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

[ii] Trimble AT, Donaldson SH. Ivacaftor withdrawal syndrome in cystic fibrosis patients with the G551D mutation. J Cyst Fibros. 2018 Mar;17(2): e13-e16. doi: 10.1016/j.jcf.2017.09.006. Epub 2017 Oct 24. PMID: 29079142.