



February 14, 2023

Office of Governor Ron DeSantis
State of Florida
The Capitol
400 S. Monroe St.
Tallahassee, FL 32399

Dear Governor Ron DeSantis,

On behalf of more than 1,800 people with cystic fibrosis (CF) in Florida, we write to express our support for SB 46, which would require insurers to apply third-party assistance to out-of-pocket maximums and other patient cost-sharing requirements. 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 46 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 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.

We urge you to support SB 46 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 Florida.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight", is centered below the text "Sincerely,". The signature is fluid and cursive.

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