



March 3, 2020

Representative **NAME**

Address Line 1

Address Line 2

City, State Zip

Dear Representative **NAME**:

On behalf of the 590 people with cystic fibrosis (CF) in Kentucky, we are writing to express our support for HB 72, which would require insurers to apply third party financial assistance to out-of-pocket maximums and any other cost-sharing requirements. While copay assistance is a short-sighted fix for systemic issues that face our health care system, solutions to address affordability and sustainability cannot come at the expense of patients' health and financial wellbeing.

Please support HB 72 to help protect access to quality, specialty therapies for people with CF.

Cystic fibrosis is a life-shortening genetic disease that requires individuals to take multiple therapies every day to address its manifestations. People with CF rely on meaningful health insurance to access high quality, specialized care that has dramatically improved length and quality of life. In the 1950s, people with CF were not expected to live to attend preschool but today more than half are adults. CF care is expensive, but we know the care model and treatments available are helping people live longer, healthier lives. Unfortunately, many people with CF are faced with limited insurance options that preclude them from taking full advantage of advanced care and treatments.

Accumulator programs—which prevent third-party payments from counting towards deductibles and out-of-pocket limits —place additional financial strain on people with CF who are already struggling to afford their care. According to a survey conducted by George Washington University of 2,500 people living with CF, one out of four people with CF and their families pay more than \$10,000 in out-of-pocket expenses each year, not including premiums and deductibles. In order to make ends meet, 78 percent of people received some form of financial assistance to help pay for their care in 2017.

High out-of-pocket costs have a direct, negative effect on treatment adherence for people with CF, which can lead to adverse health outcomes. In the aforementioned survey, 18 percent of people with CF skipped medication doses, 24 percent took less medicine than prescribed, and 29 percent delayed filling a prescription—all due to cost concerns. Because CF is a progressive disease, patients who delay or forgo treatment face increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations.

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 place a further burden on patients are unacceptable. The CF Foundation supports efforts that allow third party assistance to count toward deductibles and out-of-pocket limits, particularly for patients with severe and chronic conditions like CF. The Foundation urges health insurers and

pharmaceutical manufacturers to come together and discuss long-term solutions that do not place disproportionate financial pressure on patient and families.

We urge you to vote "yes" on HB 72. By supporting this bill, you will help ensure continued access to quality, specialized care for people with CF. The Cystic Fibrosis Foundation appreciates your attention to this important issue for the CF community in Kentucky.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight". The signature is fluid and cursive, with a large initial "M" and "D".

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