CYSTIC FIBROSIS FOUNDATION®

January 10, 2022

Senator Heather Sanborn, Senate Chair
Representative Denise Tepler, House Chair
Committee on Health Coverage, Insurance, and Financial Services
Cross Building, Room 220, 287-1314
Augusta, ME 04330

Dear Chairwoman Sanborn, Chairwoman Tepler, and Members of the Health Coverage, Insurance, and Financial Services Committee:

On behalf of the nearly 260 people with cystic fibrosis (CF) in Maine, we write to express our support for LD 1783/SP 0621, which would require insurers to apply third-party assistance for drugs without generic alternatives to out-of-pocket maximums and other patient 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.

Cystic fibrosis is a life-threatening genetic disease that affects more than 30,000 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 access for many people with the disease.

Accumulator programs—which prevent third-party payments from counting towards deductibles and out-of-pocket limits—can have a direct, negative effect on treatment adherence for people with CF 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. 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 respondents in the aforementioned survey said 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 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 chronic conditions like CF. The Foundation urges health insurers and pharmaceutical manufacturers to come to the table to discuss long-term solutions that do not place disproportionate financial pressure on patient and families.

We urge you to support LD 1783/SP 0621. By supporting this bill, you will 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 Maine.

Sincerely,

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