



February 4, 2021

Senator Casey Crabtree
Chair, Senate Commerce and Energy Committee

Senator Lee Schoenbeck
Vice Chair, Senate Commerce and Energy Committee

Dear Chairman Crabtree, Vice-Chairman Schoenbeck, and Members of the Senate Commerce and Energy Committee,

On behalf of the 130 people with cystic fibrosis (CF) in South Dakota, we are writing to express our support for SB 154. 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 SB 154 to help protect access to quality, specialty therapies for people with CF.

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—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 over 1,800 people living with CF and their families, over 70 percent indicated that paying for health care has caused financial problems such as being contacted by a collection agency, having to file for bankruptcy, experiencing difficulty paying for basics like rent and utilities, or having to take a second job to make ends meet. And while 84 percent of people received some form of financial assistance in 2019 to pay for their health care, nearly half reported still having problems paying for at least one CF medication or service in that same year.

High out-of-pocket costs have a direct, negative effect on treatment adherence for people with CF, which can lead to adverse health outcomes. Nearly half of those who participated in the aforementioned survey reported delaying or forgoing care—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.

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 vote “yes” on SB 154. 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 South Dakota.

Sincerely,

A handwritten signature in black ink, appearing to read 'Mary B. Dwight', with a stylized, cursive script.

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