

June 1, 2020

Office of Chairman Scott Lipps House Health Committee 77 S. High St, 13th Floor Columbus, OH 43215

Sent electronically to Willa.Bluestone@OhioHouse.gov

Dear Chairman Lipps and Members of the Health Committee,

On behalf of the nearly 1,550 people with cystic fibrosis (CF) in Ohio, we are writing to express our support for HB 469, which would require insurers to apply third party 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 well-being.

Please support HB 469 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 today 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 annual out-of-pocket limits and deductibles—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 high

need individuals such as those with 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 HB 469. 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 Ohio.

Sincerely,

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