



September 30, 2019

Honorable Judy Ward
Senate Box 203030
460 Main Capitol Bldg.
Harrisburg, PA 17120-3030

Dear Sen. Ward,

On behalf of the approximately 1,500 people with cystic fibrosis (CF) in Pennsylvania, we are writing to express our support for SB 731. 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-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 face insurance limitations that preclude them from taking full advantage of advanced care and treatments.

Accumulator programs 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.

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, particularly for high needs 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 patients and families.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight".

Mary B. Dwight
Senior Vice President, Policy & Advocacy