



June 21, 2019

Dear New York Senate Health Committee Members,

On behalf of the 1,650 people living with cystic fibrosis (CF) in New York, we are writing to express our support for SB 5942. The Cystic Fibrosis Foundation recognizes transparency laws as an important first step toward developing policies that support sustainability within the health care system and affordability for patients and families. These laws provide a window into state prescription drug spending and can inform future policies that more directly target costs.

Please support SB 5942 to allow for greater transparency in the pricing of prescription drugs.

Cystic fibrosis is a life-threatening genetic disease that causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to serious infections. As a complex, multi-system disease, CF requires an intensive daily treatment regimen including multiple medications. These medications, along with highly specialized care, have dramatically improved life expectancy and quality of life for people with CF. In the 1950s, people with CF were not expected to live to attend preschool but today, more than half of the population is adults.

Consistent access to CF medications is helping people live longer, healthier lives, but we also know the cost of these drugs can be a barrier to access for many people with the disease. In a 2018 study, researchers found that while 99 percent of people with CF were insured, 58 percent reported delaying or forgoing care due to cost. Even with the help of financial assistance, many families continue to struggle to afford critical CF drugs and are forced to make difficult tradeoffs to afford the care they need. The same 2018 study found that 18 percent of people with CF surveyed skipped medication doses, 24 percent took less medicine than prescribed, and 29 percent delayed filling a prescription—all due to cost concerns. Since CF is a progressive disease, patients without consistent access to their medications face increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations.

We understand the need to balance incentivizing innovation and preserving access to affordable drugs. CF patients have benefited greatly from new, revolutionary therapies. For the first time, there are precision medicines available to some people with CF that address the underlying cause of this disease. While new drugs can be life-changing, they are only beneficial when patients are able to afford them. It is critical that all people with CF have access to the medications needed to effectively treat their disease.

The Foundation acknowledges that transparency policies are not the sole solution to addressing affordability of prescription drugs. That said, policymakers need more information on spending trends to develop effective solutions to the problem of high prescription drug costs. SB 5942 provides an opportunity to bring more information into conversations about ensuring life-saving prescription drugs are both affordable and accessible to those who need them most.

Sincerely,

A handwritten signature in black ink, appearing to read 'Mary B. Dwight'. The signature is fluid and cursive, with the first name 'Mary' being the most prominent.

Mary B. Dwight
Senior Vice President of Policy & Advocacy

A handwritten signature in black ink, appearing to read 'Lisa Feng'. The signature is cursive and elegant, with the first name 'Lisa' being the most prominent.

Lisa Feng, DrPH
Senior Director of Policy & Advocacy