



June 7, 2019

Dear House Committee on Health Coverage, Insurance and Financial Services Members,

On behalf of the 260 people living with cystic fibrosis (CF) in Maine, we are writing to express our support for LD 1162. 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 how manufacturers establish prices and can inform future policies that more directly target costs.

Please support LD 1162 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.

While CF medications are helping people live longer, healthier lives, 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 providing 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.

The Foundation acknowledges that transparency policies are not the sole solution to addressing affordability of prescription drugs. That said, policymakers need more information on how manufacturers set prices to develop effective solutions to the problem of high prescription drug costs. Moreover, and more immediately, advance notice can give consumers time to budget and plan for increases in the prices of the drugs they depend on. LD 1162 provides an opportunity to bring more information into conversations about ensuring access to life-saving prescription drugs for 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 a long horizontal stroke extending to the right.

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 a large initial "L" and a long horizontal stroke.

Lisa Feng, DrPH
Senior Director of Policy & Advocacy