



June 4, 2019

Dear Senate Committee,

On behalf of the 430 people living with cystic fibrosis (CF) in Oregon, we are writing to express our support for HB 2658. 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 HB 2658 to allow for greater transparency in prescription drug spending.

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.

CF medications help 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 2017 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 2017 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 spending trends 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. HB 2658 provides an opportunity to bring more information into conversations about ensuring access to life-saving prescription drugs for those who need them most.

Sincerely,



Mary B. Dwight
Senior Vice President of Policy & Advocacy



Lisa Feng, DrPH
Senior Director of Policy & Advocacy