Cystic Fibrosis and Pulmonary Fibrosis are diseases marked by scarring in the lungs. Tissue deep in the lungs becomes thick, stiff and scarred. The scarring is called fibrosis. As the lung tissue becomes scarred, it interferes with a person's ability to breathe. Most cases of pulmonary fibrosis have no known cause. There is no cure for either of these diseases. Some people with idiopathic pulmonary fibrosis live only about three to five years after diagnosis. Most children with cystic fibrosis do not live into adulthood.

The Oregon Pulmonary Fibrosis/ Lung Transplant Support Group is a support group for individuals with pulmonary fibrosis and their families. We offer support in dealing with stress associated with pulmonary fibrosis and transplants, help teach about transplant-related issues and ensure that no patient feels scared or alone in dealing with this disease. I know firsthand the problem of and the need to address and understand prescription drug costs, however, HB 2387 has major flaws that could impede work towards a cure and patient access to critical medication.

As someone with who suffered from cystic fibrosis and as a survivor of a double lung transplant, the medications I take are not cheap and I understand the burden of co-pays and other out-of-pocket expenses but this is a complex issue with multiple facets that cannot be resolved by the very narrow focus that HB 2387 takes.Numerous factors are at play, including robust negotiations between manufacturers, payers, and pharmacy benefit managers (PBMs). Yet the bill being considered does not capture this complexity, or consider the out-of-pocket costs that are of most interest to patients; costs that are determined by the insurance plan rather than the manufacturer.

The requirements these bills propose ignore the tremendous value, both to individual patients and to society, from innovative therapies, which cannot be captured in a single line item "cost." Not only do innovative medicines result in better health outcomes for patients, but they frequently lead to increased productivity and decreased overall healthcare costs (e.g., due to fewer hospitalizations, surgeries, and physician office visits). Constant doctor appointments are something my family (and wallet) are all too familiar with. If there is a treatment that will help myself and others live a normal life and will help cut down on the amount of time and money spent in appointments, I want to make sure we accelerate its arrival, not delay it. HB 2387 poses a direct threat to the companies working to find cutting edge treatments for illnesses like pulmonary fibrosis.

HB 2387 will impose burdensome and costly reporting requirements on small biotechnology companies, the engine of innovation, by seeking data that does not align with the realities of how drugs are developed (e.g., early research and development efforts are nonlinear, and often fail in the clinic). By forcing these companies to divert limited resources to accounting activities, these requirements could reduce their ability to actually focus on developing new and innovative treatments.

We all agree that high healthcare costs need to be addressed, but this type of legislation, which is not patient-centered and stands to impede scientific and medical innovation, is simply not the answer. I ask you to protect the development of lifesaving treatments that can help myself and others with cystic and pulmonary fibrosis by rejecting this misguided legislation.

Sincerely,

Sandy Metheany

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