



March 3, 2026

Committee on Financial Institutions, Insurance and Technology  
Ohio State Senate  
1 Capitol Square, 1st Floor  
Columbus, OH 43215

Dear Honorable Members of the Senate Committee on Financial Institutions, Insurance and Technology:

On behalf of the more than 1,750 people living with cystic fibrosis (CF) in Ohio, we write to express our support HB 229 (Deeter), which makes several important reforms to the practices of Pharmacy Benefit Managers (PBMs). PBMs are third-party companies that manage prescription drug benefits on behalf of health insurers and employers, playing an important role in negotiating drug prices and determining which medications are covered. In recent years, some PBM practices have led to increased out-of-pocket costs, reduced access to necessary medications, and disruptions in care for individuals with complex conditions like cystic fibrosis. HB 229 would help ensure PBM practices prioritize patient access and affordability by increasing transparency and curbing tactics that can drive up costs or restrict access to care.

#### **About Cystic Fibrosis**

Cystic fibrosis is a progressive, genetic disease that affects the lungs, pancreas, and other organs. There are close to 40,000 children and adults living with cystic fibrosis in the United States, and CF can affect people of every racial and ethnic group. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. As a complex, multi-system disease without a cure, CF requires an intensive treatment regimen including multiple medications. For people with CF, it is not uncommon to take seven therapies every day, and as many as 20.<sup>1</sup>

While advances in CF care are helping people live longer, healthier lives, we also know that the cost of care is a barrier for many people with the disease. According to a 2024 study conducted by the Cystic Fibrosis Foundation and the Dartmouth Institute, over a third of people with CF delayed or went without at least one aspect of their CF care in the last year due to cost concerns, including skipping medication doses, taking less medicine than prescribed, delaying filling a prescription, or skipping a treatment altogether.<sup>2</sup> Because CF is a progressive disease, patients who delay or forgo treatment—even for as little as a few days—face increased risk of lung exacerbations, costly hospitalizations, and potentially irreversible lung damage.<sup>3</sup>

#### **Pharmacy Benefit Manager Reform**

PBMs play a significant role in the prescription drug supply chain, but their unchecked practices often contribute to high prescription drug costs and can create barriers to patient access. Current PBM behaviors frequently prioritize their own financial interests over the needs of patients and health plans, and their cost containment strategies have created a convoluted system that patients and their providers struggle to navigate and can result in barriers to care. We believe the provisions contained in HB 229 are meaningful reforms that will improve access and affordability for patients by regulating the business and financial structure of PBMs. The Foundation supports the following provisions in HB 229:

<sup>1</sup> Sawicki, G. S., Sellers, D. E., & Robinson, W. M. (2009). High treatment burden in adults with cystic fibrosis: challenges to disease self-management. *Journal of cystic fibrosis*, 8(2), 91-96.

<sup>2</sup> Van Citters, A. D., et.al. (2025). Financial and healthcare tradeoffs associated with cystic fibrosis care in the United States: A cross-sectional study. *Journal of Cystic Fibrosis*. Available at: <https://doi.org/10.1016/j.jcf.2025.12.021>

<sup>3</sup> Trimble AT, Donaldson SH. Ivacaftor withdrawal syndrome in cystic fibrosis patients with the G551D mutation. *J Cyst Fibros*. 2018 Mar;17(2): e13-e16. doi: 10.1016/j.jcf.2017.09.006. Epub 2017 Oct 24. PMID: 29079142.

## Transparency and Accountability

The current lack of transparency in PBM practices obscures critical information about drug pricing and payments, ultimately contributing to high drug prices.<sup>4</sup> HB 229 includes provisions that allow the Ohio Superintendent of Insurance to review essential information from PBM records including rebate arrangements, administrative fees, and the actual cost of drugs, encouraging greater transparency and accountability in PBM operations. This will illuminate inefficiencies and unfair pricing practices, creating pressure to reduce costs for patients. This legislation also holds PBMs accountable through licensing rules. As lawmakers search for ways to curb prescription drug spending, increased transparency is an important step to developing targeted strategies to address affordability and access barriers impacting patients.

## Ban Patient Steering

HB 229 includes a provision that prohibits patient steering, a practice where PBMs channel prescriptions to their own wholly owned retail, mail order, or specialty pharmacies as a condition for coverage or the lowest copayment tier.<sup>5</sup> This practice leads to significant additional profits for PBMs<sup>6,7</sup> at the expense of limiting patient choice, disrupting continuity of care, and preventing patients from accessing pharmacies with specialized expertise on their condition. Banning patient steering will ensure that patients have the freedom to choose their pharmacy based on factors like quality of care, specialized knowledge of CF medications and coverage, and proximity, rather than being directed by financial incentives for the PBM. This is particularly vital for CF patients who often rely on specialty pharmacies and established relationships with pharmacists who understand their complex treatment regimens.

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HB 229 offers an opportunity to make PBM practices more transparent and hold them accountable. We urge you to support and advance this critical legislation to help individuals living with CF and other chronic conditions access and afford the medications they need. Please contact Amanda Attiya, State Policy Specialist, at [aattiya@cff.org](mailto:aattiya@cff.org) or 240-482-2879 with any questions about this important issue for the CF community in Ohio.

Sincerely,



Mary B. Dwight  
Chief Policy & Advocacy Officer  
Senior Vice President, Policy & Advocacy  
Cystic Fibrosis Foundation

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<sup>4</sup> U.S. Federal Trade Commission Office of Policy Planning. (2024). Pharmacy Benefit Managers: The Powerful Middlemen Inflating Drug Costs and Squeezing Main Street Pharmacies. Available at: [https://www.ftc.gov/system/files/ftc\\_gov/pdf/pharmacy-benefit-managers-staff-report.pdf](https://www.ftc.gov/system/files/ftc_gov/pdf/pharmacy-benefit-managers-staff-report.pdf)

<sup>5</sup> House Committee on Oversight and Accountability. (2024).

<sup>6</sup> Federal Trade Commission. (2024). Pharmacy Benefit Managers: The Powerful Middlemen Inflating Drug Costs and Squeezing Main Street Pharmacies. Available at: [https://www.ftc.gov/system/files/ftc\\_gov/pdf/pharmacy-benefit-managers-staff-report.pdf](https://www.ftc.gov/system/files/ftc_gov/pdf/pharmacy-benefit-managers-staff-report.pdf)

<sup>7</sup> Three Axis Advisors. (2020) Sunshine in the Black Box of Pharmacy Benefits Management Florida Medicaid Pharmacy Claims Analysis. Available at: <https://static1.squarespace.com/static/5c326d5596e76f58ee234632/t/5e384f26fc490b221da7ced1/1580748598035/FL+Master+Final+Download.pdf>