



March 24, 2026

Committee on Health and Human Services
Rhode Island House of Representatives
State House
82 Smith Street
Providence, RI 02903

Dear Honorable Members of the House Committee on Health and Human Services:

On behalf of the more than 100 people living with cystic fibrosis (CF) in Rhode Island, we write to express our support for HB 7189, which prohibits pharmacy benefit managers (PBMs) from engaging in a practice known as “patient steering” by requiring that PBMs provide equal reimbursement rates and terms to non-affiliated pharmacies as to affiliated ones. 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 like patient-steering 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 7189 would help ensure PBM practices prioritize patient access and affordability by curbing a tactic 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 20.¹

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.² 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.³

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.

¹ 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. <https://doi.org/10.1016/j.jcf.2008.09.007>

² Van Citters, A. D., Carey, K., Ren, C. L., Phan, H., Beidler, L., King, J. R., ... & Dieni, O. (2025). Financial and healthcare tradeoffs associated with cystic fibrosis care in the United States: A cross-sectional study. *Journal of Cystic Fibrosis*. <https://doi.org/10.1016/j.jcf.2025.12.021>

³ Trimble, A. T., & Donaldson, S. H. (2018). Ivacaftor withdrawal syndrome in cystic fibrosis patients with the G551D mutation. *Journal of Cystic Fibrosis*, 17(2), e13-e16. <https://doi.org/10.1016/j.jcf.2017.09.006>

HB 7189 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.⁴ This practice leads to significant additional profits for PBMs^{5,6} 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.

HB 7189 offers an opportunity to hold PBMs accountable and ensure their decisions are patient-centered. 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 or 240-482-2879 with any questions about this important issue for the CF community in Rhode Island.

Sincerely,



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⁴ House Committee on Oversight and Accountability. (2024).

⁵ Federal Trade Commission. (2024). Pharmacy Benefit Managers: The Powerful Middlemen Inflating Drug Costs and Squeezing Main Street Pharmacies. https://www.ftc.gov/system/files/ftc_gov/pdf/pharmacy-benefit-managers-staff-report.pdf

⁶ Three Axis Advisors. (2020), Sunshine in the Black Box of Pharmacy Benefits Management Florida Medicaid Pharmacy Claims Analysis. <https://static1.squarespace.com/static/5c326d5596e76f58ee234632/t/5e384f26fc490b221da7ced1/1580748598035/FL+Master+Final+Download.pdf>