CYSTIC FIBROSIS FOUNDATION®

March 26, 2026

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

Dear Honorable Members of the Senate 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 SB 2253, SB 2462, and SB 2466, which strengthen regulation of pharmacy benefit managers (PBMs) and ensure that third-party financial assistance counts towards patients' out-of-pocket obligations. 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 and insurer 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. Together, these bills would help ensure that PBM and insurer practices prioritize affordability and uninterrupted access to medically necessary care, and that patients' health and financial wellbeing are not sacrificed in the ongoing, systemic debate between payers and pharmaceutical companies about prescription drug pricing.

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

[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

BETHESDA HEADQUARTERS
4550 MONTGOMERY AVE.
SUITE 1100 N
BETHESDA, MARYLAND 20814
T: 800.FIGHT.CF
W: CFF.ORG
E: INFO@CFF.ORG

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 SB 2253, SB 2462, and SB 2466 are meaningful reforms that will improve access and affordability for patients by regulating the business of PBMs and health plans.

Ban Copay Accumulator Programs
SB 2253 prohibits PBMs and plans from implementing copay accumulator programs, which prevent third-party payments from counting towards deductibles and out-of-pocket limits. These programs effectively increase out-of-pocket costs for patients and place additional financial strain on people with CF who are already struggling to afford their care. We recognize that copay assistance is problematic—it allows pharmaceutical companies to charge payers high prices while shielding many individual patients from those costs. It is reasonable that payers would push back against this tactic, as drug costs continue to increase. Nevertheless, patients with chronic diseases like CF often struggle to afford their care and rely on copay assistance to access vital medications. While over 80% of respondents to the aforementioned survey received some form of financial assistance to help pay for their health care, more than a third still delayed some aspect of their care due to medical bills.

We understand the challenge insurers face in managing the rising cost of drugs and that copay assistance programs mask bigger cost and affordability issues in the health care system. However, cost containment strategies that further burden patients are unacceptable. Accumulators are especially challenging for a disease like CF, which has no generic options for many of the condition's vital therapies. The situation has become even more dire as a company that manufactures CF therapies recently reduced the amount of copay assistance available for people enrolled in accumulator programs.

Ban Spread Pricing
SB 2462 aims to prevent PBMs working with the Rhode Island Medicaid program from charging a managed care organization (MCO) more than what the PBM reimburses the pharmacy for the same drug, a practice known as spread pricing. This practice allows PBMs to profit from the difference between what they charge a plan and what they pay the dispensing pharmacy. In fact, a study conducted by the Ohio Auditor of State found that PBMs retained more than $200 million over the course of a year through spread pricing, [4] and a similar report from the Kentucky Cabinet for Health and Family Services found that PBMs retained $123 million in spread in 2017.[5] Spread pricing inflates overall plan costs and can contribute to artificially high out-of-pocket costs for drugs, including CF therapies such as CFTR modulators, which already have high price tags. Prohibiting spread pricing removes a significant layer of hidden profit for PBMs and reduces overall plan costs, helping to ensure fairer pharmacy reimbursement practices.

Ban Patient Steering
SB 2466 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.[6] This practice leads to significant additional profits for PBMs[7,8] at the expense of limiting patient choice, disrupting continuity of care, and preventing patients from accessing pharmacies with specialized expertise on their

---

[4] Ohio Auditor of State. (2018). Auditor's Report: Pharmacy Benefit Managers Take Fees of 31% on Generic Drugs Worth $208M in One-Year Period. https://ohioauditor.gov/news/pressreleases/Details/5042
[5] Kentucky Cabinet for Health and Family Services. (2019). Medicaid Pharmacy Pricing Opening the Black Box. https://chfs.ky.gov/agencies/ohda/Documents1/CHFSMedicaidPharmacyPricing.pdf
[6] House Committee on Oversight and Accountability. (2024).
[7] 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
[8] 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

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.

****

We urge you to support SB 2253, SB 2462, and SB 2466 to help ensure continued access to quality, specialty care for people with CF. The Cystic Fibrosis Foundation appreciates your attention to this important issue for the CF community in Wisconsin. Please contact Amanda Attiya, State Policy Specialist, at aattiya@cff.org or 240-482-2879 with any questions about this issue.

Sincerely,

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