CYSTIC FIBROSIS FOUNDATION®

July 25, 2023

The Honorable Ron Wyden
Chairman
Committee on Finance
221 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Mike Crapo
Ranking Member
Committee on Finance
239 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Wyden and Ranking Member Crapo:

On behalf of the nearly 40,000 children and adults with cystic fibrosis in the United States, we thank you for introducing the *Modernizing and Ensuring PBM Accountability (MEPA) Act* to enhance accountability for pharmacy benefit managers (PBMs), address the opaque influence PBMs have in our health care system.

The Cystic Fibrosis Foundation is a national organization dedicated to curing cystic fibrosis (CF). We invest in research and development of new CF therapies, advocate for access to care for people with CF, and fund and accredit a network of specialized CF care centers. 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 life-threatening infections. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. If left untreated, infections and exacerbations caused by CF can result in irreversible lung damage, and the associated symptoms of CF lead to early death, usually by respiratory failure. Transformative therapies—such as CFTR modulators—have been paramount in changing what it means to live with CF. However, PBM cost containment strategies have created a convoluted system that patients struggle to navigate and often results in significant barriers to care.

PBMs cause significant barriers to care for people with CF in navigating insurance. This is largely due to the lack of understanding of the role of PBMs in coverage decisions and evolving strategies that PBMs put in place to mitigate their own costs and those of their clients, which add out-of-pocket costs or administrative burden for patients. **We believe the provisions contained in the MEPA Act are meaningful reforms that will improve the experience for patients, in addition to regulating the business and financial structure of PBMs.**

In response to the Committee's April hearing titled "Pharmacy Benefit Managers and the Prescription Drug Supply Chain: Impact on Patients and Taxpayers," we submitted a statement for the record urging any legislative proposal to increase transparency, oversight, and enforcement of PBM practices.[1] We appreciate the Committee worked to prioritize patient needs by including significant and actionable transparency provisions, allow for review of PBM practice and establish accountability measures, prohibiting unfair and deceptive practices like de-linking PBM compensation from the cost of the

[1] CFF Statement for the Record in response to "Pharmacy Benefit Managers and the Prescription Drug Supply Chain: Impact on Patients and Taxpayers" found at: https://www.cff.org/media/29481/download?inline

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prescription drug, and requiring the Office of the Inspector General to study and report on prescription drug price mark-ups in Medicare Part D. We believe these measures will make a meaningful difference for patients and work to ensure that all health care stakeholders have information they need to ensure that patients' interests are being served.

As the Senate seeks to pass a comprehensive PBM reform package this fall, we urge you to work with your colleagues to prioritize patient interest that fall outside the jurisdiction of the Finance Committee, including legislation to address maximizers, alternative funding programs, and accumulators.

Third-party entities such as maximizers—many of which are owned by PBMs—and alternative funding programs add complexity to an already opaque system. Maximizers often outsource a patient's drug coverage to a third-party entity that sets the patients' cost-sharing at a level to maximize use of manufacturer copay assistance. Alternative funding programs also rely on third-party entities that seek to enroll patients in manufacturer patient assistance programs that provide free drugs, which are usually intended for people without insurance. New coverage tactics emerge frequently, requiring patients and care teams to consistently learn and adapt to new, opaque, and confusing policies. PBMs are often at the center of these challenges.

PBMs and insurers are increasingly implementing accumulator programs as well—which prevent third-party payments from counting towards deductibles and out-of-pocket limits and therefore increasing out-of-pocket costs for patients. Many people with CF rely on third-party financial assistance to cover some of the costs associated with their care, as CF is an expensive disease. The CF Foundation recognizes that copay assistance programs mask bigger cost and affordability issues; however, cost containment strategies like accumulator programs that further burden patients are unacceptable.

The CF Foundation recommends including the *Help Ensure Lower Patient Copays Act* (HELP Copays Act; S. 1375) in to any PMB reform legislation. This bill reduces patient administrative and financial barriers imposed by PBMs and payers by 1) requiring payers to apply third party assistance to out-of-pocket maximums and other patient cost-sharing requirements; and 2) ensuring any item or service covered by a health plan is considered part of their essential health benefits (EHB) package. Together, these policies would prohibit accumulators, maximizers, and alternative funding programs in federally-regulated insurance plans, eliminating some of the most problematic PBM practices for patients.

Thank you for your leadership on this important issue. The CF Foundation stands ready to work with you to ensure patients' health and financial wellbeing are not sacrificed in the ongoing systemic debate among payers, PBMs, and drug manufacturers.

Sincerely,

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