

September 18, 2024

The Honorable Ron Wyden

Chairman
Committee on Finance
U.S. Senate
221 Dirksen Senate Office Building
100 Constitution Avenue, NE
Washington, DC 20510

The Honorable Bernie Sanders

Chairman
Committee on Health, Education, Labor & Pensions
U.S. Senate
428 Dirksen Senate Office Building
100 Constitution Avenue, NE
Washington, DC 20510

The Honorable Maria Cantwell

Chairwoman
Committee on Commerce, Science, and Transportation
U.S. Senate
511 Hart Senate Office Building
120 Constitution Ave NE
Washington, DC 20510

The Honorable Cathy McMorris Rodgers

Chairwoman
Committee on Energy & Commerce
U.S. House of Representatives
2188 Rayburn House Office Building
45 Independence Ave SW
Washington, DC 20515

The Honorable Jason Smith

Chairman
Committee on Ways and Means
U.S. House of Representatives
1011 Longworth House Office Building
1 Independence Ave SE
Washington, DC 20515

The Honorable Mike Crapo

Ranking Member
Committee on Finance
U.S. Senate
239 Dirksen Senate Office Building
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Washington, DC 20510

The Honorable Bill Cassidy, M.D.

Ranking Member
Committee on Health, Education, Labor & Pensions
U.S. Senate
455 Dirksen Senate Office Building
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Washington, DC 20510

The Honorable Ted Cruz

Ranking Member
Committee on Commerce, Science, and Transportation
U.S. Senate
167 Russell Senate Office Building
2 Constitution Ave NE
Washington, DC 20510

The Honorable Frank Pallone

Ranking Member
Committee on Energy & Commerce
U.S. House of Representatives
2107 Rayburn House Office Building
45 Independence Ave SW
Washington, DC 20515

The Honorable Richard Neal

Ranking Member
Committee on Ways and Means
U.S. House of Representatives
372 Cannon House Office Building
27 Independence Ave SE
Washington, DC 20515

The Honorable Virginia Foxx
Chairwoman
Committee on Education & the Workforce
U.S. House of Representatives
2176 Rayburn House Office Building
45 Independence Ave SW
Washington, DC 20515

The Honorable Robert C. “Bobby” Scott
Ranking Member
Committee on Education & the Workforce
U.S. House of Representatives
21011 Rayburn House Office Building
45 Independence Ave SW
Washington, DC 20515

CC:

The Honorable Charles Schumer
Majority Leader
United States Senate
322 Hart Senate Office Building
129 Constitution Ave NE
Washington, D.C. 20510

The Honorable Mitch McConnell
Minority Leader
United States Senate
317 Russell Senate Office Building
2 Constitution Ave NE
Washington, D.C. 20510

The Honorable Mike Johnson
Speaker of the House of Representatives
U.S. House of Representatives
568 Cannon House Office Building
27 Independence Ave SE
Washington, D.C. 20510

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
2433 Rayburn House Office Building
45 Independence Ave SW
Washington, D.C. 20510

Dear Chairs Wyden, Sanders, Cantwell, McMorris Rodgers, Smith and Foxx and Ranking Members Crapo, Cassidy, Cruz, Pallone, Neal and Scott:

The undersigned patient groups, representing millions of patients across the United States living with chronic and acute conditions, hear consistently from people with these conditions about the many challenges they face accessing life-changing or life-saving medications. Reforms are needed in many areas to help patients access the medications they need in a more timely and more affordable manner—including reforms to the practices of pharmacy benefit managers (PBMs).

PBM policies have a direct impact on whether patients can access and afford their medications. PBMs dictate decisions about access to, and affordability of, medications—controlling which drugs are available and at what price; what hoops patients have to jump through; and which pharmacies patients can use.

We therefore urge you to pass meaningful PBM reform by the end of this year that ensures transparency and accountability for PBMs and their practices, and prioritizes the needs of patients.

For our organizations, this means:

- Ensuring transparency and accountability to allow for systemic reform, and so that all stakeholders, including patients, are working with the same level of information to inform healthcare decision-making;

- Banning spread pricing;
- De-linking PBM compensation from the cost of prescription drugs; and
- Addressing insurance-mandated step therapy practices that present barriers for patients accessing medically-necessary medications.

PBMs create significant barriers to care for people with chronic and acute conditions navigating insurance. This is largely due to the role of PBMs in coverage decisions and the evolving strategies that PBMs put in place. As Congress looks toward passing a comprehensive PBM reform package by the end of the year, we urge you to include the following proposals.

Increasing Transparency

There is increased pressure on patients to make informed choices about their care and prescription drug medications. However, there is very little transparency to guide patients as they navigate our health system. Transparency measures for PBMs and insurers would mean patients receive better information about coverage policies for specialty drugs. By having clear information on the requirements for obtaining specialty medications, patients can access their treatments more efficiently without undue burden. Transparency around formulary design would also allow patients and their health care providers to have confidence that clinical evidence is driving coverage decisions. Additionally, this transparency could give advocates and researchers the information and data they need, and facilitate system-level reforms as-needed.

We urge Congress to advance proposals that expand and improve transparency measures for PBMs and insurers to ensure patients receive better information about coverage policies.

Ensuring Accountability

As demonstrated in the recent FTC interim report,¹ vertical integration and increased consolidation over the last few decades have exacerbated the uneven power dynamic between PBMs and consumers. The pharmacy benefit management market has become extremely concentrated, and the largest PBMs are vertically integrated with the largest health insurers, as well as specialty and retail pharmacies. As a result, in 2023, the top three PBMs processed nearly 80 percent of the approximately 6.6 billion prescriptions dispensed by U.S. pharmacies, and account for nearly 70 percent of all specialty drug revenue.² This consolidation allows PBMs to exercise significant control over which drugs are available for patients, and at what price. In addition, this consolidation—and the related lack of fair and transparent reimbursement practices for non-affiliated pharmacies—reduces patient choice, allowing PBMs to control which pharmacies patients can use to access their prescribed medications.

Given the harm vertical integration and consolidation has had on patient access to essential medications, we urge Congress to pass proposals that will more effectively hold PBMs accountable for their anticompetitive actions and hold PBMs accountable for providing appropriate services and access to their enrollees. These reforms will benefit patients and the healthcare system as a whole.

¹ Federal Trade Commission, “Pharmacy Benefit Managers: The Powerful Middlemen Inflating Drug Costs and Squeezing Main Street Pharmacies,” Interim Staff Report. July 2024. Available at: https://www.ftc.gov/system/files/ftc_gov/pdf/pharmacy-benefit-managers-staff-report.pdf

² *Id.*

De-Linking PBM Compensation

Right now, PBMs are incentivized to prefer medications that offer the best rebates, instead of the ones that are the least expensive, or perform the best clinically. This practice has the dual result of driving up list prices while limiting access to less expensive treatment options, including lower-cost biosimilars or generic medications.

Our organizations support policy proposals that would "de-link" PBM compensation based on the list price of a drug as a condition of entering a contract with plans, across all plan types. Service fees should not be connected to the price of a drug, discounts, rebates, or other fees. Instead, PBM compensation should be limited to a flat dollar amount service fee. We believe that a flat service fee would be a fairer process for purchasing and distributing medications.

The de-linking provision will bring much-needed reform to these areas, to help people access and afford the medications they need to treat and manage their conditions. Our organizations believe this measure will make a real difference for patients' out-of-pocket costs and access to necessary therapies, and support efforts to increase transparency.

Banning Spread Pricing

For similar reasons, our organizations support banning spread pricing across all plan types. Spread pricing, in which an insurer is charged more for a prescription drug than the pharmacy is reimbursed, leads to inflated drug costs that impact patients. The PBM has an incentive to maximize the size of the spread, which means that patients, drug purchasers and distributors pay more than is necessary for medications and treatments.

Addressing Utilization Management Practices via Step Therapy Reform

PBMs play a powerful role in determining what access patients have to their medications. Their unique role allows them to determine what medications are covered by payors, what tier those medications are placed on, and what pharmacies people can use to get their medications. One form of utilization management that is particularly concerning for the patient and provider community is insurance-mandated step therapy because it can delay access to needed medications for months and lead to severe or irreversible health outcomes.

Insurance-mandated step therapy utilization management requires that patients demonstrate that an insurer-preferred treatment does not work before the plan will cover the treatment initially selected by the patient and their provider. Some step therapy practices can require between three to five medications to fail a person with a chronic disease before access to the prescribed medication is approved.

The Safe Step Act (S. 662/H.R. 2630) was added as an amendment to S. 1339, the PBM Reform Act, by a vote of 20-1. The bill is a crucial safeguard for patients and would ensure that employer-sponsored health plans offer a timely and medically reasonable step therapy exceptions process. The Safe Step Act complements legislation that has passed in 38 states. This policy will directly impact patient access to essential medications, and we strongly urge Congress to include the Safe Step Act in the PBM reform package.

Millions of people who live with chronic and acute health conditions need Congress to act this fall and pass comprehensive and commonsense PBM reforms. These reforms have bipartisan, bicameral support and the potential to improve access and affordability of medications patients need. Thank you for considering our recommendations, and we encourage you to use our groups as a resource. If you have any questions, or would like to meet to discuss these priorities, please reach out to Steffany Stern (National Multiple Sclerosis Society) at Steffany.stern@nmss.org or 612-718-8924.

Sincerely,

American Diabetes Association
American Liver Foundation
Arthritis Foundation
CancerCare
Cancer Support Community
Chronic Disease Coalition
Crohn's & Colitis Foundation
Cystic Fibrosis Foundation
Epilepsy Foundation
Foundation for Sarcoidosis Research
Hydrocephalus Association
Leukemia & Lymphoma Society
Lupus Foundation of America
Muscular Dystrophy Association
National Multiple Sclerosis Society
National Psoriasis Foundation
National Organization for Rare Disorders
Susan G. Komen
The AIDS Institute
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