

July 26, 2023

The Honorable Ron Wyden
Chairman
Senate Finance Committee
221 Dirksen Senate Office Building
100 Constitution Avenue, NE
Washington, DC 20510

The Honorable Mike Crapo
Ranking Member
Senate Finance Committee
239 Dirksen Senate Office Building
100 Constitution Avenue, NE
Washington, DC 20510

Dear Chairman Wyden, Ranking Member Crapo and Members of the Senate Finance Committee:

The undersigned patient groups, representing millions of patients across the United States living with cancer, cystic fibrosis, epilepsy, hemophilia, and multiple sclerosis, write to thank you for the introduction of *The Modernizing and Ensuring PBM Accountability (MEPA) Act* to enhance accountability for pharmacy benefit managers (PBMs), address misaligned incentives that contribute to high prescription drug costs for patients, prevent spread pricing within the Medicaid program, improve access to pharmacies, and increase oversight of the prescription drug supply chain.

Our organizations regularly hear from people with chronic conditions about the many challenges they face accessing life-changing or life-saving medications across the drug supply chain. The MEPA Act will bring much needed reforms to these areas to help people with chronic disease access and afford the medications they need.

We believe that the provisions contained in the MEPA Act are meaningful and sound reforms that address the current challenges that contribute to the opaqueness of the U.S. healthcare system. As various Congressional committees have worked to pass PBM reform in the 118th Congress, our organizations have identified several priorities to ensure that PBM reform prioritizes the needs of patients and ensures transparency and accountability of PBMs and their practices. Our organizations previously made the following recommendations of any PBM legislation:

- Proposals be advanced that improve transparency so that all stakeholders, including patients, are working with the same level of information to inform health-care decision making.
- Establish an entity that has jurisdiction to examine PBM behavior and the authority to hold PBMs accountable and impose effective accountability measures.
- Align incentives within the system to ensure that PBMs have a responsibility to act on what is best for the patient.
- Prohibit unfair and deceptive pricing models including spread-pricing and arbitrary claw backs of payments and ban PBMs from using discriminatory formularies and require all savings to be passed through to patients.

Our groups were pleased to find many of these priorities reflected within the MEPA Act. We appreciate that the Committee worked to prioritize patient needs by including meaningful and actionable transparency provisions, allow for review of PBM practice and establish accountability measures, prohibiting unfair and deceptive practices like spread-pricing, de-linking PBM compensation from the cost of the 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 significant difference for patients and work to ensure that all health-care stakeholders have information they need to ensure that patients' interests are being served.

Senate passage of a comprehensive PBM reform package should be a priority post August Recess

We applaud the work the Finance Committee has done to date on PBM reform; however, as the full Senate works towards assembling a PBM reform package this fall, we urge you to work with your colleagues to prioritize patient interests in areas that fall outside the jurisdiction of the Finance Committee.

We believe that the Senate can build upon the patient-centric principles of the MEPA by addressing PBMs' role in utilization management practices that determine the process that patients must follow to access their medications by including legislative proposals like the **Safe Step Act (S.652)** and the **HELP Copays Act (S.1375)**. Currently, PBMs determine what medications are covered by payors, what tier those medications are on, and what pharmacies people can use to get their medications. As costs and utilization of medications have increased, health plans and PBMs have implemented strict utilization management practices – such as prior authorization and step therapy – to minimize the use and cost liability for medications.

Utilization management practices present significant hurdles for patients and prescribers and cause real delays and barriers for people with chronic diseases in accessing the treatments they need. Unduly restrictive access criteria result in increased nonadherence and dangerous delays that can put patients at risk. Twenty-four percent of physicians report that prior authorization requirements have led to a serious adverse event for patients in their care, and 16% of physicians say that these practices have led to a patient's hospitalization¹. Some step therapy practices can require between three to five medications to fail a person with a chronic disease before access to the provider and individual's medication of choice is approved.

Additionally, copay accumulator programs (a feature implemented by PBMs and/or insurers that prevent third-party financial assistance from counting towards a patient's deductible and out-of-pocket maximum), further burden patients. High cost-sharing under current plan designs directly impacts patient access, and many patients with chronic conditions rely on third-party financial assistance to cover some of the costs associated with their care. Without assistance, these patients now may be required to pay thousands of dollars out-of-pocket for their specialty medications all at once. When faced with high out-of-pocket costs, patients do not use their medications appropriately – skipping doses in order to save money or abandoning treatment altogether.

Conclusion

Millions of people who live with chronic diseases and conditions need the Senate to act this fall and pass comprehensive and common sense PBM reform to improve access to and affordability of the medications they need to live their lives. Please utilize our groups as resources during this process. If we can be of assistance, please reach out to Leslie Ritter, AVP of Federal Government Relations, at Leslie.Ritter@nmss.org. Thank you for commitment to comprehensive PBM reform to better access to prescription drugs for patients, we look forward to continued collaborations.

Sincerely,

The National Multiple Sclerosis Society
Can Do Multiple Sclerosis
Consortium of MS Centers
Cystic Fibrosis Foundation
Epilepsy Foundation
Hemophilia Federation of America
International Organization of Multiple Sclerosis Nurses
Multiple Sclerosis Association of America
Multiple Sclerosis Foundation
MS Views and News
Muscular Dystrophy Association
National Hemophilia Foundation
National Organization for Rare Disorders
Susan G. Komen®
United Spinal

cc: Senate Committee on Health, Education, Labor and Pensions, Majority Leader Chuck Schumer, and
Minority Leader Mitch McConnell

ⁱ American Medical Association. 2019 AMA prior authorization (PA) physician survey. <https://www.ama-assn.org/system/files/prior-authorization-survey.pdf>