National
Multiple Sclerosis
Society

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Statement for the Record
Subcommittee on Health, Employment, Labor, and Pensions
"Profits Over Patients: The PBM Business Model Under Scrutiny"

On behalf of the nearly one million people living with multiple sclerosis (MS) in the United States, we thank you for holding a hearing to investigate the pharmacy benefit manager (PBM) business model. We appreciate your efforts to look deeper at the healthcare system to identify stakeholder tactics that create significant financial and administrative barriers to care. We urge you to prioritize patient-centered solutions that protect access to affordable, high quality MS care and medications for those living with MS and other chronic conditions.

MS is an unpredictable, often disabling, disease of the central nervous system, which interrupts the flow of information within the brain and between the brain and the body. Symptoms range from numbness and tingling to blindness and paralysis. The progression, severity, and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are moving us closer to a world free of MS for the estimated one million people living with MS in the United States. The National Multiple Sclerosis Society (the Society) works to cure MS while empowering people affected by MS to live their best lives. To fulfill this mission, we fund cutting-edge research, drive change through advocacy, facilitate professional education, collaborate with MS organizations around the world, and provide services designed to help people affected by MS move their lives forward.

The high cost of treating MS, especially the price of MS disease-modifying therapies, makes them a prime target for PBMs and insurers to limit access.

MS is a highly expensive disease. The average total cost of living with MS is $88,487 per year.[1i] MS disease-modifying therapies (DMTs) are the biggest cost of living with the disease, with individuals with MS spending an average of $65,612 more on medical costs than individuals who don't have MS. The total estimated cost to the U.S. economy is $85.4 billion per year.[2]

Evidence demonstrates that early and ongoing treatment with an MS DMT is the best way to manage disease course, prevent accumulation of disability, and protect the brain from damage due to MS. Due to the complexity of MS, and how the disease presents differently in each individual, a wide variety of medications with a range of mechanisms of action and modes of administration are needed. There are now more than twenty DMTs on the market, including generic options, and these medications have transformed the treatment of MS over the last three decades. Unfortunately, the pricing trajectory for these medications has made affordability a challenge for many. As of 2026, the median annual cost for a brand MS DMT was nearly $118,000. Additionally, time on the market for MS DMTs does not correlate with lower prices, as 7 out of 9 that have been on the market for at least 12 years are priced over $100,000 annually and continue to see regular price increases.

In 2016, the Society released comprehensive recommendations to improve access to MS medications, which calls on stakeholders across the healthcare and drug supply chain system to work together to make medications more affordable, simplify the process for accessing them, and ensure that prices and coverage information are transparent. In the decade since they were released, MS Activists and Society staff have worked diligently to bring these recommendations to life. We believe there is no single solution that can fully reverse the trend toward ever-increasing drug prices and payer policies that inhibit or delay access to medically necessary therapies. We have consistently called on all stakeholders to engage in conversations to drive solutions and to bring forward solutions for their industry.

Unfortunately, due to their high price, MS DMTs have often been a target of egregious PBM practices that create immense barriers to patients who depend on these medications for treatment. Despite having no direct relationship with individual patients, PBMs control: what medications insurers cover; the amount patients pay out-of-pocket; policies that can limit access, like step therapy and prior authorization; and even what pharmacy patients must use. Simply put, PBM policies have a direct impact on whether people with MS can access and afford their medications.

[1] B. Bebo et al. A Comprehensive Assessment of the total economic burden of multiple sclerosis in the United States. ECTRIMS 2021. 15, October, 2021.
[2] B. Bebo et al. A Comprehensive Assessment of the total economic burden of multiple sclerosis in the United States. ECTRIMS 2021. 15, October, 2021.

Access to affordable, comprehensive health insurance coverage is essential for people with multiple sclerosis (MS) to get the care and treatments they need to live their best lives.

When it comes to insurance coverage, plan benefits must be robust enough so that people with MS can access the care required for optimal health. An affordable plan means nothing if it does not offer the comprehensive benefits that people with MS rely on to live their best lives. But enrollment is not always as user-friendly or cut and dry as it should be. People living with MS sometimes enroll in a plan that they believe to be comprehensive, and then learn certain specialists, procedures, or even drugs aren't covered. Similarly, they may enroll in a plan that requires patients and their providers to navigate through multiple types of prohibitive processes, just to access prescribed treatments and medications.

> *In Ohio, Bari T. who lives with MS, shared "[a]fter consulting with a broker, I changed plans to one that I was told would better meet my needs. However, I've had nothing but problems since—including prior authorization delays and requests for step therapy for a medication I've been stable on for years. I'm so frustrated with how time consuming, inconvenient, and inconsistent healthcare has become."*

MS requires coordinated medical care to control symptoms, prevent complications, and reduce hospitalizations using medication and a multidisciplinary care team. This team may be comprised of primary care providers, neurologists, urologists, mental health professionals, physical and occupational therapists, speech-language pathologists, ophthalmologists, and dietitians, among others. Comprehensive care also encompasses access to prescription medications, which could potentially include a range of symptom-management medications in addition to the aforementioned DMTs.

If people living with MS enroll in a health plan that doesn't offer adequate coverage, or a plan that refuses to pay for the care they need, they can be on the hook for enormous out-of-pocket burdens or major bills, and at increased risk of accruing medical debt.

Negotiated prices for medications should benefit the person using and paying for the medication.

The current healthcare system is driven by rebates and other price concessions, based on negotiations between pharmaceutical manufacturers, insurance companies, PBMs, and others within the drug supply chain. This can make it difficult to understand the true cost to the system of any given medication. Additionally, determining the role that PBMs play in prescription drug pricing, consumer access, and quality is difficult to assess given a lack of publicly available information. For example, pharmaceutical companies have a list price for their medications, but PBMs can then negotiate drug prices, rebates, and price concessions with the pharmaceutical companies on behalf of insurers. However, insurers often lack clarity regarding the prices PBMs have negotiated. PBMs then contract with pharmacies and negotiate the reimbursement amount that the pharmacies will receive from the insurers. Rebate benefits are then seldom passed on to the person taking the medication or their insurer.

This system of repeated cost-containment tactics frequently results in patients being left with an increased cost burden and no clarity into why or how. While we know that these fees are contributing to higher out-of-pocket costs for patients, the fees themselves are opaque. Greater transparency is needed into the wide array of fees that PBMs charge other stakeholders in the healthcare system, especially PBM subsidiaries, which can drive up prescription drug costs, particularly for those who rely on specialty medications like people living with MS.

It is apparent that PBMs have caused egregious markups of several MS medications. This practice was illustrated in a 2025 Federal Trade Commission (FTC) Report, which uncovered that the three largest PBMs marked up several generic specialty medications dispensed at their affiliated pharmacies. Three therapies that individuals living with MS rely on to manage their disease were listed in the report: dalfampridine (Ampyra®), which was marked up 2,435%, dimethyl fumerate (Tecfidera®), which was marked up 2,121%, and glatiramer (Copaxone®), which was marked up 136% over the estimated acquisition cost (NADAC) on the commercial market in 2022. Individuals affected by MS were concerned by the finding that the PBM industry, which was established to control prescription drug spending, would manipulate the market to increase its profits.

PBMs create significant access barriers that make it challenging—and sometimes impossible—for people living with MS to get the care and treatments they need.

Because of their outsized role in managing prescription drug benefits, PBMs also play a powerful role in determining what access people with MS have to their DMTs and symptom management medications.

Formulary design

People living with MS have a uniquely burdensome experience because DMTs are usually classified as specialty medications and, as a result, placed on specialty tiers with higher cost-sharing requirements. This is true not just of brand medications, but generics and biosimilars as well. Medications on specialty tiers often require that enrollees pay a coinsurance as opposed to a flat copay and this coinsurance can be as much as 40% of the list price of the medication. These out-of-pocket costs are unaffordable to most, or require individuals and families to make huge sacrifices in order to pay for their medications—often facing huge bills in the thousands of dollars, especially in the first months of the plan year.

While generic medications can play a critical role in prescription drug affordability, their placement on specialty tiers means that they remain unaffordable for many MS patients. They often have the same high cost-sharing as the brand alternatives meaning that, even if their list prices are significantly lower, the out-of-pocket costs for patients remain high. In some instances, brand drugs may even receive a more favorable formulary placement than their generic alternatives, meaning the out-of-pocket costs for the brand drug can actually be lower than for the generic.

Gretchen M., who lives with MS, in Massachusetts was upset when her PBM called to steer her into switching to a generic form of her DMT shortly after it entered the market. However, after consulting with her neurologist, she took advantage of the generic's temporary lower out-of-pocket cost for the first year. The next year, she was shocked when the PBM then moved the generic to the same cost tier as her brand DMT. She said, "It felt like a bait and switch tactic by the PBM with me, losing out on the long term cost benefit."

Utilization Management

Beyond out-of-pocket costs, PBMs implement additional utilization management techniques connected to formulary design that make accessing needed medications more difficult. Both prior authorization and step therapy are common techniques used to minimize the use and cost liability of DMTs. Prior authorization requires healthcare providers to request coverage for a medication based on medical necessity on behalf of their patients despite already having prescribed it, thus indicating its necessity. Step therapy requires patients to try and "fail" on at least one lower tier medication before an insurer will approve coverage of the medication originally prescribed by their healthcare provider. Both practices cause delays in proper treatment which can lead to long-term consequences such as disease progression and permanent accumulation of disability.

Bill M., who lives with MS, in Georgia shared, "[s]ince my diagnosis in 2016, I have successfully managed my multiple sclerosis with Gilenya which has allowed me to remain in the work force as a business owner. In 2024, when I changed insurance, I faced step therapy and prior authorization challenges. Despite more than 7 years of success on Gilenya, my insurance company denied my neurologists orders and tried to force me onto a different medication. For six weeks I was forced to go without my daily oral MS DMT while my neurologist fought the denials. Due to the prolonged period of missed doses, I was required to go through a time consuming and costly 24-hour clinical observation period. Throughout the process - my biggest fear while being off an MS DMT or being forced to switch to a new one - was the possibility of having a relapse that I would not be able to recover from."

An analysis of patient claims denials from 2020 to 2024 showed that 91% of MS patients starting a new therapy experience an initial rejection and after one year, 43% are still denied.[3] Further, the same analysis found that only 26% of patients who did not gain approval after a year found an alternative treatments, with the remaining 74% foregoing treatment.

[3] Ehrenberg, R., Copley, K., Gupte, S. The Impact of Formulary Controls on Commercially Insured Patients in Five Chronic Therapeutic Areas. [White paper]. IQVIA. 2025. https://www.iqvia.com/locations/united-states/library/white-papers/the-impact-of-formulary-controls-on-commercially-insured-patients-in-five-chronic-therapeutic-areas.

According to a 2024 survey of practicing physicians done by the American Medical Association, physicians and their staff spend an average of 13 hours a week completing prior authorization approvals. 82% of respondents reported that the prior authorization process can lead to treatment abandonment and 93% report care delays.[4]

> *In Wisconsin, Mary O., was prescribed Gabapentin to manage the neuropathy in her fingers and toes due to MS. However, after experiencing "intolerable side effects" her neurologist prescribed Lyrica which was proven effective for patients who could not tolerate Gabapentin. She shared, "My health insurance's PBM required my physician to complete a prior authorization in order for me to get [Lyrica], yet her request was denied. Before my insurance would cover Lyrica, the PBM required that I first fail Gabapentin at a dose of 900 mg, three times a day. This was three times the dose that I was already finding intolerable. My doctor sent a second prior authorization explaining the need which was also rejected. After I tried to increase the Gabapentin, a third prior authorization was sent but it was denied as well. After weeks of back-and-forth with the PBM, my only option was to accept a suboptimal treatment for my symptoms."*

Copay accumulators, maximizers, and alternative funding programs

In addition to utilization management practices, PBMs have begun to implement other tactics that ultimately make it more difficult for individuals to access their much-needed prescription medications. One increasingly common tactic is the use of copay accumulator programs. Copay accumulator programs prohibit third-party copay assistance from counting toward an enrollee's annual deductible or maximum out-of-pocket costs despite the assistance being paid directly to insurers. Enrollees also often do not know about these programs until their assistance runs out for the year and they are faced with the entirety of their deductible still to be paid. As a result, many enrollees may never reach their deductible and face higher out-of-pocket costs. For people who financially rely on copay assistance, this may lead to interruptions in, or even non-adherence to, treatment.

As more and more states pass laws banning the use of copay accumulator programs in fully funded plans, PBMs have pivoted to copay maximizer programs and alternative funding programs (AFPs) as well. Copay maximizer programs are also referred to as manufacturer coupon optimization. The goal of these programs is to maximize the available manufacturer copay assistance by steering enrollees toward third-party companies to cover specific medications, often specialty medications like MS DMTs. These third-party companies will calculate what an enrollee could receive in financial copay assistance in a year and set that as the out-of-pocket maximum to ensure they are collecting as much as possible from drug manufacturers. As a result, this ensures that enrollees only ever meet their out-of-pocket maximum at the end of the plan year and nothing is counted toward their annual deductible or out-of-pocket maximum for any other medical services. This inevitably delays other, much-needed care due to increased out-of-pocket costs that are unaffordable to enrollees.

[4] https://www.ama-assn.org/system/files/prior-authorization-survey.pdf

AFPs, typically used in ERISA plans, shift the cost for specialty medications away from the insurer and employer. They do this through work with third-part entities and the use of what is known as the essential health benefits (EHB) loophole. The EHB loophole occurs when PBMs contract with a third-party company to distribute specialty medications and that third-party company then deems that the medications are not considered EHBs. The loophole makes enrollees appear underinsured because their healthcare provider will receive a denial letter for coverage of their specialty medication with no alternatives suggested. The enrollee is then directed to either pay out of pocket or use the third-party entity to seek out "free" medication. This medication is obtained because the third-party entity seeks out compensation via manufacturers' patient assistance program or other independent charitable foundations. This seeking out of assistance can then lead to delays in treatment and any assistance ultimately secured by the AFP will not count toward the enrollee's deductible or out-of-pocket maximum.

Regardless of which of these practices are implemented and utilized by PBMs, healthcare providers and enrollees face the brunt of repercussions. More time spent by providers fighting for coverage with PBMs means less time to see patients. Each additional hurdle in access for enrollees means further delays in treatment which can have permanent health consequences. The impact of these policies are felt beyond access to medications as lengthening deductible windows delays access to other costly care such as imaging.

While outside of the Committee's jurisdiction, the Society urges Congress to swiftly pass HELP Copays Act (H.R. 6423) that would eliminate these insurer tactics that shift costs to patients and ensure that any payment made on behalf of a patient is applied to their deductibles and out-of-pocket maximums. The legislation would also close a loophole that allows some employer-sponsored plans to classify certain covered drugs as "non-essential" and instead require any covered service by a health plan is considered an EHB.

Vertical integration

PBMs are often no longer independent entities, as PBMs, insurers, and specialty pharmacies are increasingly owned by the same company. This vertical integration of the healthcare system calls into question PBMs' claim that requiring a particular pharmacy is best for patient care. While this practice may be better for business, it does not take patients' needs and concerns into account. A person living with MS should have the option to get their medication from a pharmacy that is convenient for their location and life circumstances. Requiring a particular pharmacy chain, a single specialty pharmacy, or a mail-order pharmacy does not put the patient's needs first and may introduce access barriers. Many factors contribute to an individual's pharmacy choices. Some examples include: individuals who lack a secure place to receive deliveries (e.g., those who rent apartments, live in rural areas without mail delivery, or are housed in insecure situations), individuals who face discrimination because of their medical condition and need to receive medications and supplies in private, individuals with cognitive impairments who benefit from an established trusted relationship with their pharmacist, or those who require a pharmacy close to their home because of mobility concerns/inability to drive.

The Society has heard numerous stories from individuals living with MS about challenges with designated specialty pharmacies that can result in individuals being without medications for a period of time, jeopardizing their health. These stories range from not receiving on-time medication deliveries, to medication deliveries being left outside in bad weather under improper storage conditions, to not being able to reach customer service in a timely manner. Even when their assigned pharmacy comes with poor customer service and business practices that put their health at risk, patients have no other options.

Additionally, in a 2024 report, the FTC found that PBMs exert substantial influence over independent pharmacies by imposing unfair, arbitrary, and harmful contractual terms that can affect independent pharmacies' ability to remain in business and serve their communities. Independent pharmacies are primarily located in rural areas and underserved metropolitan neighborhoods, and they may act as a vital, sole, or primary healthcare provider in these communities. By limiting access to these pharmacies, PBMs can have an outsized influence on the health of these communities.

Important steps have been taken to provide oversight and regulate PBMs, but the work is not over.

The Society has called upon Congress to act expediently to pass comprehensive and common-sense PBM reforms for over seven years. We were thankful to see meaningful first steps from Congress through passage of the Consolidated Appropriations Act of 2026 (H.R.7148) which included key provisions to enhance PBM transparency, accountability, and reform compensation models. While these changes will not solve all access issues for patients, they express a clear intent from Congress to provide greater transparency across the prescription drug supply chain and are significant steps in the right direction toward greater oversight of the PBM industry.

The Society also was pleased to see the announcement earlier this year of a settlement between the Federal Trade Commission and Express Scripts, which includes sweeping reforms to help lower patient costs, adjust formulary preference of high-cost drugs, and provide greater transparency into the relationships between all involved stakeholders.

However, as evidenced by today's hearing, there is still a great deal of work to be done to shine a light on the opaque business practices of PBMs and bring down costs for patients, especially for those enrolled in employer-sponsored coverage. Most recently, we provided comments on the Department of Labor's proposed rule that would require providers of PBM services to make detailed disclosures to fiduciaries of employer-sponsored self-insured group health plans. We were happy to also see congressional bipartisan and bicameral interest to treat PBMs as fiduciaries in employer-sponsored group plans through the PBM Fiduciary Accountability, Integrity, and Reform (FAIR) Act (S.3549/H.R. 6837). Together the proposed rule and this legislation would provide greater visibility and accountability to help protect patients from PBM practices that restrict access to care.

The Society also supports the PBM Kickback Prohibition Act (H.R. 7895) that would prohibit PBMs from providing direct or indirect referral fees to brokers, consultants, or similar intermediaries in exchange for steering employer-sponsored health plans to a PBM. However, we urge this Committee to consider stronger enforcement language that outlines civil penalties under ERISA and better defines referrals to avoid noncompliance from PBMs who characterize these fees as something else, such as "consulting services."

While regulation and oversight of PBMs has lagged, their tactics continue to evolve as they implement new practices that exacerbate existing access and affordability barriers. An example of a more recent trend that is gaining attention is PBM's utilization of Group Purchasing Organizations (GPOs), which are subsidiaries of the three big PBMs, thus deepening the current vertical integration structure. Many PBMs have outsourced their data processing and rebate negotiation to GPOs. Any policy solutions related to sharing rebates with enrollees and transparency into additional fees must also apply to GPOs and all PBM subsidiaries. GPOs are just one example that demonstrates the need for Congress to act decisively, and to do so sooner rather than later.

People affected by MS celebrate recent progress towards addressing PBM practices and urge Congress to continue working towards high-impact comprehensive reform.

We remain encouraged by recent congressional scrutiny of PBM practices, and by recent legislative progress that is meaningful for many coverage populations. Yet we continue to recommend that Congress work towards a more comprehensive PBM reform package that brings about savings and relief for people enrolled in all plan types—including employer-sponsored coverage. Additionally, we urge the Committee to consider how to strengthen the oversight and enforcement of PBM policies to ensure that the intended benefit reaches the patients who have been waiting on this critical reform.

We urge Congress to advance proposals including, but not limited to, the following recommendations:

- **Expand and improve transparency measures for PBMs and insurers to ensure patients receive better information about coverage policies.** Ensuring transparency and accountability would facilitate systemic reform, and allow all stakeholders, including patients, to work with the same level of information to inform healthcare decision-making.

- **Ban 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. This policy change holds the potential to bring down costs and increase affordability for patients.

- **De-link PBM compensation 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. De-linking could bring much-needed reform that will help people access and afford the medications they need to treat and manage their conditions.

- **Address insurance-mandated utilization management practices that present barriers for patients accessing medically-necessary medications.** Two forms of utilization management that are particularly concerning for the patient and provider community are prior authorization requirements, and insurance-mandated step therapy. Both can delay access to needed medications for months and lead to severe or irreversible health outcomes.

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Overall, we believe that the choice of treatment for people living with MS should be between the individual and their healthcare provider, and the profit margin of the PBM should not be relevant in the decision. Any cost savings should be realized by the consumer, not by the PBM.

The Society thanks the Committee for engaging in these important conversations. If you have any questions or would like to discuss our comments further, please contact Ashleigh Tharp, Associate Vice President of Federal Government Relations at ashleigh.tharp@nmss.org.

Sincerely,

Steffany Stern
Vice President, Advocacy
National Multiple Sclerosis Society