



**National  
Multiple Sclerosis  
Society**

June 21, 2023

**Re: Support SB 192 (Pharmacy Benefit Manager) transparency**

Oregon House Committee on Rules,

On behalf of the National Multiple Sclerosis Society (the Society), thank you for your attention to the role that PBMs play in Oregon's healthcare system. People with multiple sclerosis (MS) need more information to make educated choices about their health insurance and the medications they need to live their best lives. Unfortunately, PBMs currently operate in the middle of the pharmaceutical distribution chain and very little information about them is available for patients and regulators to utilize in healthcare decision-making. The Society supports SB 192 which aims to bring more transparency into PBM business practices.

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.

MS is a highly expensive disease. The average total cost of living with MS is \$88,487 per year<sup>i</sup>. The total estimated cost to the U.S. economy is \$85.4 billion per year, and the direct medical cost to live with MS is an average of \$65,612 more than a person who does not live with MS<sup>ii</sup>. Evidence demonstrates that early and ongoing treatment with a MS disease-modifying therapy (DMT) is the best way to manage the disease course, prevent the accumulation of disability, and protect the brain from damage due to MS<sup>iii</sup>. 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 30 years. Unfortunately, these DMTs are incredibly expensive. The annual cost for individuals on an MS DMT ranges from \$57,202 to \$92,719, depending on an individual's age and gender<sup>iv</sup> and people with MS stay on these medications for years.

The full range of MS DMTs represent various mechanisms of action and routes of administration with varying efficacy, side effects, and safety profiles. No single agent is 'best' for all people living with MS<sup>v</sup> and, as MS presents differently in each person, every person's response to a DMT will vary. It is common for people with MS to move through several different DMTs throughout their life as they may "break-through" on a medication, or have disease activity, and need to try a different DMT.

***The Role of PBMs in the US Healthcare system and trajectory of MS DMT prices***

PBMs have played an increasingly important - but often hidden - role in the U.S healthcare system. PBMs manage prescription drug benefits for health insurers, Medicare Part D drug plans, large employers, and other payors. While initially created in the 1960's to help control the cost of prescription drugs, their role has evolved and today they are powerful players in the American healthcare system.



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PBMs play a fundamental role in determining the cost of prescription drugs for payors, influencing the access to medication that people with MS and other patients need, and determining how much pharmacies are paid for these medications.

When the first MS DMT came to market in 1993, the price range was \$8,000 to \$11,000 for one year of treatment. The price of MS therapies has dramatically risen since that time. The annual median price for MS DMTs has increased nearly \$34,000 in less than 10 years. As of January 2023, the median annual price of brand MS DMTs is close to \$98,000. While not identical, most brand MS DMTs have seen similar pricing trajectories which are not sustainable for people with MS or the U.S. healthcare system. Cost increases have also impacted MS symptom management medications. For example, H.P. ActharGel (Acthar), approved in 1952, is used as a short-term treatment for acute exacerbations of MS. For years, this medication was priced at less than \$40 per vial. However, today, a vial of Acthar is priced at around \$40,000- approximately 140,000% more expensive than when it was approved 68 years ago<sup>vi</sup>. The price increases and additional out-of-pocket costs associated with these medications' present real hurdles and barriers to people affected by MS.

#### ***PBMs role in formulary development and restrictions to access***

PBMs play a significant role in the access that people with MS have to their DMTs and symptom management. As costs have increased, health plans and PBMs employ increasingly strict utilization management practices to minimize the use and cost liability for these therapies. These practices present significant hurdles for prescribers and real barriers for people with MS. While PBMs often cite part of their role as keeping pharmaceutical and health costs down, there are documented examples that PBM practices can add costs to the healthcare system overall and inhibit patient care. For example, physicians in the United States complete an average of 33 prior authorization requests every week, taking an average of 14.4 hours to process.<sup>vii</sup>

Too often, formularies designed by PBMs, and health insurers are driven not by medical practice, but by rebates in the system. For example, according to a 2020 staff report from the House Committee on Oversight and Reform, Teva Pharmaceuticals exerted pressure on PBMs by tying contractual rebates on Copaxone 20 mg/ml to adding Copaxone 40 mg/ml to their formularies<sup>viii</sup>.

There is often little transparency into how formularies or step therapy protocols are developed, especially for MS DMTs, where there are no publicly available algorithms describing how to progress through the different MS DMTs. In 2019, in response to a Society funded survey, people with MS reported that the greatest challenge in getting their DMT comes from insurance companies<sup>ix</sup>. Through the years, people with MS and their healthcare providers have described egregious step therapy practices and prior authorization delays that have resulted in MS exacerbations, worsening health, and increased costs to the healthcare system. Examples of these practices include requiring three to five DMTs to fail a person with MS prior to access the individual's medication of choice, requiring someone to use a DMT they already know does not work for them, and requiring people with needle phobia to



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use self-injectable medications even though oral medications are available. Rather than “getting the right medication to the right person” as the industry describes, these practices result in nonadherence and dangerous delays to people getting on the DMTs that will work for them. With every delay, people with MS risk disease activity and underlying progression from which they may not recover.

Additionally, increasing vertical integration of PBMs and payors, rebating, and other business-related practices often result in formulary placement of medications that often steers individuals towards more expensive medications, while generics and biosimilars are available. For example, PBMs often place generic drugs and biosimilars in higher formulary tiers alongside brand medications, thus negating the cost savings to the health system and the patient. We have seen this practice in the MS space, as MS generics, due to higher cost than regular generic medications, are covered more like specialty medications, resulting in higher cost sharing for people with MS. Likewise, a PBM may prefer a higher cost drug because it will increase their revenue so, despite lower cost alternatives being available, a higher cost product receives favorable formulary placement. We believe that the choice of therapy for people with MS should be between the patient and their healthcare provider, and the profit margin of the PBM should not be relevant in the decision

### ***Policy Changes To Promote Transparency and Accountability are Needed***

There is increased pressure on people with MS and other chronic health conditions to make good choices about the cost of their care and prescription drug medications, yet there is very little true transparency throughout the healthcare system, and people often have very little information about price and cost to guide these decisions. We believe that the language in SB 192 is a good step to increase transparency to help people affected by MS. The bill will help patient, patient groups, doctors, health systems, and the state of Oregon, better understand why formularies are designed the way they are, incentivize those practices that are fair and promote transparency, and will protect patients.

The Society’s full set of policy recommendations for PBM reform is outlined below. We realize that some of these recommendations fall outside current bill language, however, **we urge you to pass SB 192 and to continue to advance PBM reform to ensure all Oregonians have access to the life-changing therapies they need to live their best lives.** The Society supports PBM reform which:

- Ensures transparency by requiring disclosure of specific costs, prices, reimbursements, fees, mark ups, discounts and aggregate payments received with respect to their PBM service.
- Prohibits unfair and deceptive pricing models including spread-pricing and arbitrary claw backs of payments, in addition to requiring pass-through pricing models.
- Requires oversight and reporting on PBM behavior and allows the Attorney General to take legal action when a PBM is found in violation of the law.
- Allows for patients to have a choice of the pharmacy where they receive their medications.



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- Allows patients to receive the benefits from rebated savings and pay the lesser amount of copay/co-insurance, the amount charged by the PBM to the pharmacy, or the cost of the drug.
- Includes a substantial monetary penalty for those PBMs who act in violation of the law.
- The Society has concerns with the lack of financial penalties in SB 192; we prioritize accountability within licensure of PBMs. As written, there is no incentive to not be transparent.

Thank you again for your attention to the issue of the high cost of prescription medications for Oregonians. If you have any questions about our comments or recommendations, please contact [Seth.Greiner@mss.org](mailto:Seth.Greiner@mss.org).

Regards,

A handwritten signature in blue ink, appearing to read 'Seth Greiner', with a stylized, scribbled underline.

Seth Greiner  
National Multiple Sclerosis Society  
Senior Manager, Advocacy  
WA | OR | MT | ID | AK

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<sup>i</sup>Bebo, Bruce et. al. The Economic Burden of Multiple Sclerosis in the United States: Estimate of Direct and Indirect Costs. *Neurology* May 2022, 98 (18) e1810-e1817; DOI: 10.1212/WNL.0000000000200150. <https://n.neurology.org/content/98/18/e1810> (accessed May 4, 2022).

<sup>ii</sup> Bebo, Bruce et. al. The Economic Burden of Multiple Sclerosis in the United States: Estimate of Direct and Indirect Costs. *Neurology* May 2022, 98 (18) e1810-e1817; DOI: 10.1212/WNL.0000000000200150. <https://n.neurology.org/content/98/18/e1810> (accessed May 4, 2022).

<sup>iii</sup> Costello, K. et al. MS Coalition. "The Use of Disease Modifying Therapies in Multiple Sclerosis: Principles and Current Evidence. September 2019. [https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/DMT\\_Consensus\\_MS\\_Coalition.pdf](https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/DMT_Consensus_MS_Coalition.pdf) (accessed May 20, 2022)

<sup>iv</sup> Bebo, Bruce et. al. The Economic Burden of Multiple Sclerosis in the United States: Estimate of Direct and Indirect Costs. *Neurology* May 2022, 98 (18) e1810-e1817; DOI: 10.1212/WNL.0000000000200150. <https://n.neurology.org/content/98/18/e1810> (accessed May 4, 2022).

<sup>v</sup> MS Coalition. The Use of Disease Modifying Therapies in Multiple Sclerosis: Principles and Current Evidence. [http://www.nationalmssociety.org/getmedia/5ca284d3-fc7c-4ba5-b005-ab537d495c3c/DMT\\_Consensus\\_MS\\_Coalition\\_color](http://www.nationalmssociety.org/getmedia/5ca284d3-fc7c-4ba5-b005-ab537d495c3c/DMT_Consensus_MS_Coalition_color). Accessed December 26, 2018.

<sup>vi</sup> H.P. Acthar Gel Prices, Coupons and Patient Assistance Programs. <https://www.drugs.com/price-guide/h-p-acthar-gel>. (Accessed March 1, 2023).

<sup>vii</sup> 2019 AMA Prior Authorization (PA) Survey. American Medical Association. June 2020. [www.ama-assn.org/system/files/2020-06/prior-authorization-survey-2019.pdf](http://www.ama-assn.org/system/files/2020-06/prior-authorization-survey-2019.pdf)

<sup>viii</sup> Drug Pricing Investigation Teva-Copaxone. Staff Report Committee on Oversight and Reform. U.S. House of Representatives. September 2020. <https://oversight.house.gov/sites/democrats.oversight.house.gov/files/Teva%20Staff%20Report%2009-30-2020.pdf> (Accessed May 3, 2020).

<sup>ix</sup> National MS Society. Quantifying the Effect of the High Cost of DMTs. Market Research Report. August 2019. <https://nms2cdn.azureedge.net/cmssite/nationalmssociety/media/msnationalfiles/advocacy/nms-research-report-full-access-to-ms-medications.pdf>. (Accessed February 15, 2023).