

From: Seth Greiner

Sent: Thursday, December 4, 2025 4:27 PM

To: DCBS Rx.Prices * DCBS <Rx.Prices@dcbs.oregon.gov>

Cc: PARRA Sofia E * DCBS <Sofia.E.PARRA@dcbs.oregon.gov>

Subject: RE: MS Society, written testimony, DCBS 2025 annual hearing on Rx prices

Sofia,

Thank you and the staff for a(nother) well run hearing. I would also, if possible, like to draw the members attention to the MS Society submitted comments to the PDAB on their 2026 legislative recommendations, which speak directly to the issue of UPLs brought up at the end of the hearing. These were submitted to the PDAB on 11/11/2025.

Again, thank you and the staff.

Seth Greiner

MS Society



Oregon Division of Financial Regulation
Oregon Prescription Drug Affordability Board
350 Winter St. SE
Salem, OR 97309

November 11, 2025

RE: National Multiple Sclerosis Society, 2025 policy recommendation comments

Members of the Oregon Prescription Drug Affordability Board:

Thank you for your continued engagement with all stakeholders and for focusing on the patient's perspective. The National Multiple Sclerosis Society (Society) appreciates the Prescription Drug Affordability Board's (Board) leadership and investigation into the high cost of prescription medications. We encourage the Board to continue its review of all practices that limit access to needed life-changing therapies and increase the price that patients pay for those therapies.

Multiple sclerosis (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. 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.

Costs of living with MS

People with MS have a variety of healthcare needs including, but not limited to, addressing neurological symptoms, emotional and psychological issues, rehabilitation therapies to improve and maintain function and independence, and long-term care. These needs vary dramatically from person to person and can change year-to-year as the disease progresses.

MS is a highly expensive disease, with the average total cost of living with MS calculated at \$88,487 per year¹. MS may impact one's ability to work and can generate steep out-of-pocket costs related to medical care, rehabilitation, home & auto modifications, and more. For individuals with MS, medical costs are an average of \$65,612 more than for individuals who do not live with this disease. Disease-modifying treatments (DMTs) are the single largest component of these medical costs. As of February 2024, the median annual brand price of MS DMTs was more than \$107,000. Five out of seven of the DMTs that have been on the market for at least 13 years are priced at over \$100,000 annually and continue to see regular price increases.

Upper Payment Limits authority

The Society views upper payment limit (UPL) authority as having the potential to lower out-of-pocket costs for patients by directly addressing the dollar cost of prescription medications. High out-of-pocket costs are typically due to co-insurance, which is when the patient must pay a

¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9109149/>



percentage of the wholesale acquisition cost (WAC), or list price, as opposed to a flat copay amount. This is especially true for MS DMTs. A lower UPL would in turn create lower out-of-pocket costs for those who must pay co-insurance.

The Society continues to support the establishment of UPLs and recommends the Board put such authority forward in your legislative recommendations. We look forward to commenting on the Board recommendations for any MS-related medications identified as cost burdensome. We applaud the multiprong approach in identifying these medications by referencing data as well as continuing to engage with stakeholders who are impacted by these costs

Pharmacy Benefit Managers ‘spread pricing’

When a Pharmacy Benefit Manager (PBM) charges a health plan more for a medication than what the PBM reimburses the issuing pharmacy, keeping this difference as PBM revenue, this is called ‘spread pricing’. The Society advocates prohibiting unfair and deceptive pricing models including spread pricing and would recommend any financing use ‘pass through’ pricing models.

Expanded PDAB scope

The Society understands the price of the medication is but one aspect of what makes access to these high-cost prescriptions out of reach for many people with MS and other conditions. The Society will continue to look at the entire healthcare system and encourages legislatures and boards like this to continue their work in addressing all aspects of the prescription drug supply chain that get between patients and their medications. The Society would support efforts to increase the scope and authority of the current PDAB to encompass more of the prescription drug system and its actors.

Medicaid prescription drug ‘carve outs’

Most states, including Oregon, which contract with Medicaid managed care organizations (MCOs) for their state Medicaid services include their Medicaid pharmacy benefits and health benefits into a single contract. However, some states “carve out” or de-link their prescription drug coverage from healthcare managed care, meaning the health benefit and drug benefit are separate contracts with the state. The Society encourages the state to explore all options which could lower the cost of prescription drugs but cautions that any system should be analyzed and monitored for instances of excessive utilization management and/or limited formularies to ensure such reforms do not create new barriers to accessing needed medications.

The Society thanks the Board for its ongoing focus and engagement on this key issue for all Oregonians. Please continue to consider the Society and myself as references as the board continues its work.

Respectfully,

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