



**National
Multiple Sclerosis
Society**

August 14, 2024

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

**RE: National Multiple Sclerosis Society, Upper Payment Limits & Affordability Review Process
comments**

Dear Members of the Oregon Prescription Drug Affordability Board:

Thank you for taking the time to consult all stakeholders and for the opportunity to provide direct comments regarding upper payment limits. This letter is to provide clarity to the National Multiple Sclerosis Society (the Society) position related to upper payment limits and the affordability review process.

UPLs related to copays and MS infusible products

The Society views the establishment of upper payment limits (UPL) as creating the potential to lower out of pocket costs for patients. High out of pocket costs are typically due to co-insurance, which is when the patient must pay a percentage of the wholesale acquisition cost (WAC), or list price, as opposed to a flat copay amount. This is especially true for MS disease-modifying therapies (DMTs). A lower UPL would in turn create lower out-of-pocket costs for those who must pay co-insurance.

One important caveat to this is that for infused medications, which include several of the most prescribed MS DMTs, patients face significant additional costs from the administration of, and additional services attached to, an infused product. These additional costs can include infusion center fees, hospital or provider facility fees, additional provider and specialist fees, and ancillary medication charges for side effects or infusion management. A UPL would not affect this additional expense and, as a result, might not substantially lower patient out-of-pocket costs for the overall infused medication services.

Affordability review process

The Society sees affordability reviews as key to partially understanding prescription drug pricing within the broader healthcare system. We recommend any affordability review process include all available sources of data so long as the scientific methodology is sound, and the sources are considered both reputable and knowledgeable. These sources may include but not be limited to; all-payer databases, state-produced reports, and data and reports from other state reviews. Additionally, the long-term costs associated with MS DMTs vs. the shorter-term costs of other medications should be considered when discussing affordability.



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When undertaking the review, the Society recommends considering additional factors which could influence affordability including:

- Average monetary price concessions, discounts, or rebates the manufacturers provide to health plans and PBMs (expressed as a percentage of WAC),
- Price of therapeutic alternatives sold in the Washington State,
- Average cost to state health plans based on typical patient access to a drug,
- Impacts on patient access resulting from cost of the drug and insurance benefit design,
- Current or expected dollar value of the drug-specific patient access programs supported by the manufacturer,
- Average patient's copay or any other cost-sharing amount, and
- Any other information the manufacturer would like to provide or other factors the board determines it may need.

The Society knows that 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 entities like the Oregon Prescription Drug Affordability Board to do likewise.

Respectfully,

A handwritten signature in blue ink, appearing to read 'Seth M. Greiner'. The signature is fluid and cursive, with a large, sweeping underline that loops back under the first part of the name.

Seth M. Greiner

Senior Manager, Advocacy

Seth.Greiner@NMSS.org



ENSURING ACCESS THROUGH COLLABORATIVE HEALTH

August 16, 2024

Oregon Prescription Drug Affordability Board
Department of Consumer and Business Services
350 Winter Street NE
Salem, OR 97309-0405

Public Comments on Cost Reviews and Upper Payment Limits

Dear Members and Staff of the Oregon Prescription Drug Affordability Board:

The Ensuring Access through Collaborative Health (EACH) Coalition is a network of national and state patient organizations and allied groups that advocate for treatment affordability policies that consider patient needs first.

We applaud the board's recent decision to pause affordability reviews and work on improving the affordability review process for the remainder of 2024. We appreciate the board's willingness to acknowledge the complex nature of cost-reviews, the significant undertaking with which the board has been tasked, and the stakeholder feedback outlining concerns with the process.

We look forward to continued engagement with the board to improve the cost-review process to ensure it ultimately benefits the patients who rely on the drugs under review. We respectfully urge the board to consider the concerns of patient organizations outlined in this letter. We offer our organization as a resource to board members seeking to connect with patient organizations and patients.

Cost Reviews and UPLs Could Compromise Patient Access to Medications

While we applaud the board's commitment to supporting patients and lowering the costs of prescription medications, we are concerned that cost reviews and upper payment limits (UPLs) can further complicate an already complex healthcare marketplace and result in worse outcomes for patients.

At their core, cost reviews necessitate selecting individual drugs for review and implementing market interventions for the selected drugs. This alone puts PDABs in a position of picking winners and losers between drugs and within the broader population of Oregon patients. Individual drug reviews unnecessarily create inequities between patient populations.

While UPLs are intended to lower costs for patients, the reality is that they will create a new incentive structure for payers that could compromise patient access to the selected medications due to increased utilization management or reshuffling of formularies. This eventuality was outlined by the Centers for Medicare and Medicaid Services in their [May 3, 2024 Guidance on Medicare Drug Price Negotiation](#), "CMS is concerned that Part D sponsors may be incentivized in certain circumstances to disadvantage selected drugs by placing selected drugs on less favorable tiers compared to non-selected drugs, or by applying utilization management that is not based on medical appropriateness to steer Part D beneficiaries away from selected drugs in favor of non-selected drugs."

Additionally, many of the drugs under cost review are administered directly by physicians under a "buy and bill" model. Physician reimbursement rates are already being squeezed, and UPLs

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could additionally lower opportunities for treatment costs to be recouped. As a result, it is likely that physicians would adjust treatment recommendations to avoid facing financial deficits, leaving patients with fewer treatment options.

Finally, creating a unique pricing structure in Oregon will create state-specific conditions for coverage. We don't know yet how either insurers or manufacturers will react to state-by-state exceptions, but this has potential to cause either of these stakeholders to limit availability in the state and could cause confusion for patients and providers in the state.

Upper Payment Limits Don't Necessarily Translate to Patient Savings

Assuming that UPLs directly translate to lowered costs for patients ignores the complicated nature of our healthcare system. In our system, patients are not responsible for paying the full cost of their prescription medications nor are they allowed to freely select from the full range of treatments medically approved for their condition. Instead, these decisions are determined by their insurance company and pharmacy benefit manager (PBM). It is also these stakeholders that determine if cost-savings realized by the payer are subsequently shared with patients. Unfortunately, in most cases, they are not.

Payers in our health marketplace do not necessarily derive the most value from the lowest cost drugs. According to [reporting on PBMs by the New York Times](#), "Even when an inexpensive generic version of a drug is available, PBMs sometimes have a financial reason to push patients to take a brand-name product that will cost them much more. For example, Express Scripts typically urges employers to cover brand-name versions of several hepatitis C drugs and not the cheaper generic versions. The higher the original sticker price, the larger the discounts the PBMs can finagle, the fatter their profits — even if the ultimate discounted price of the brand-name drug remains higher than the cost of the generic."

Ultimately, this could mean insurers and PBMs place drugs subject to UPLs on higher tiers of the formulary. This could lead to higher out-of-pocket costs for patients who could face higher copay or coinsurance rates to retain access to that drug or alternatively be forced to switch to a more expensive drug that results in higher profits to their PBM.

These plan-prompted changes are collectively known as non-medical switching and were also noted in the excerpt from CMS above. Non-medical switches in medication can also cause unnecessary complications for patients. At a minimum, a switch in medication will require more doctor visits to monitor the efficacy of a new medication. Further, if the switch results in side effects or worsened outcomes, patients could face medical interventions or hospitalization and the additional costs borne out by both.

Patient Access Cannot Be Compromised

Chronic conditions are incredibly complex to treat. Each patient faces a unique experience and should be able to work with their doctor to identify the treatment that works best for them. Substituting or requiring patients to change drugs based on cost considerations instead of medical needs can disrupt continuity of care and result in complications and higher overall medical costs.

We urge this board to seriously consider the unique circumstances faced by these patients and work diligently to ensure that access to all treatments is protected. We strongly urge the board



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and staff to utilize the authority of the board to fully explore with all healthcare stakeholders how UPLs will be implemented and identify in advance any adverse impact to patients.

Identify and Resolve Patient-Reported Obstacles to Care

As we have outlined, while well-intentioned, UPLs fail to address many of the underlying causes and complicated factors that result in higher prescription drug costs for patients. Therefore, we urge the board to focus its time on identifying and addressing patient-reported obstacles to drug affordability.

Failing to resolve the underlying factors that lead to higher costs for patients can result in short-term relief and uneven benefits – aiding some but potentially leaving others with higher costs and drug accessibility challenges. Additionally, regulators should clearly define cost-saving targets, including what percentage will be patients and what will be the state or the broader healthcare system.

Ultimately, we know that defining affordability is a key aspect of the drug review process that the Oregon board is seeking to improve. We implore the board, to the extent that it is able to within statute, focus on defining affordability based on patient reported costs and concerns.

Sound Health Policy is Founded on Patient Perspectives

In continuation of that point, while our health system and the policies that impact it are complicated, one principle is simple: every change that we make and policy we implement should ultimately benefit patients. We urge the board to keep this principle as a singular focus as it evaluates the impact of its cost reviews and UPLs.

We urge the board to utilize this organization and its members as a direct conduit to understanding and incorporating patient and caregiver perspectives, as well as those of patient organizations who have an understanding of the life cycle of disease from the lens of prevention, diagnosis, and disease management.

We appreciate your laudable efforts to improve our health system and your steadfast commitment to protecting patients. We look forward to working together to achieve these goals.

Sincerely,

Ensuring Access through Collaborative Health (EACH) Coalition