



**National
Multiple Sclerosis
Society**

November 1, 2024

Washington State Health Care Authority
Washington State Prescription Drug Affordability Board
Olympia, WA 98501

RE: National Multiple Sclerosis Society, affordability review and drug selection comments

Dear Washington State Prescription Drug Affordability Board members:

Thank you for the opportunity to offer comments on issues confronting the Washington State Prescription Drug Affordability Board (Board). The National Multiple Sclerosis Society (Society) continues to appreciate and support the Board's work on lowering the cost of prescription medications for all Washingtonians. These comments are intended to provide the Board with additional context as they work to identify prescription medications which pose an undue cost burden on both the state and its residents.

Multiple sclerosis (MS) is an unpredictable disease of the central nervous system. Currently there is no cure. Symptoms vary from person to person and may include disabling fatigue, mobility challenges, cognitive changes, and vision issues. An estimated 1 million people live with MS in the United States. Early diagnosis and treatment are critical to minimizing disability. Significant progress is being made to achieve a world free of MS.

Cost of living with multiple sclerosis

MS is a highly expensive disease, with the average total cost of living with MS at \$88,487¹ per year. Medications and treatments are the biggest cost of living with the disease, with individuals spending an average of \$65,612 more on medical costs than individuals who don't have MS. MS may impact one's ability to work and can generate steep out-of-pocket costs related to drug coverage, medical care, rehabilitation, home & auto modifications, and more.

Current multiple sclerosis disease-modifying therapies

While there is no cure for MS, the availability of disease modifying therapies (DMTs) has transformed the treatment of MS over the last 30 years. Evidence indicates that early and ongoing treatment with a DMT is the best way to manage the course of the disease, prevent accumulation of disability and protect the brain from damage due to MS. There are more than 20 DMTs on the market with generics available for five of the brand DMTs. Unfortunately for people affected by MS, despite the addition of many new drugs as well as generic alternatives, the price of MS treatments has continued to rise since the first DMT was approved in 1993. This first DMT was priced at

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



**National
Multiple Sclerosis
Society**

approximately \$11,000 annually; that same drug today has a wholesale acquisition cost (WAC) of over \$126,000. It has not had any major formulaic changes. As such, any affordability review needs to put the direct patient costs front and center in any analysis.

Data sources for affordability reviews

The Society sees affordability reviews as key to partially understanding prescription drug pricing within the broader healthcare system. We recommend that any affordability review process include all available sources of data in which 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.

Specifically, the Board identified sources including the WA State All-payer Claims Database, current state boards including the Health Care Costs Transparency board, yearly submitted manufacture reporting data, Pharmacy Benefit Manager reporting data, and additional pricing information from trusted and respected databases. These sources should provide the Board with a more complete data snapshot of the pricing range and methods. Importantly, any analysis discussing the affordability of prescription drugs should differentiate between long-term usage for chronic conditions and shorter utilization for acute conditions.

Regarding overall drug utilization, the number of Washingtonians currently prescribed MS DMTs may be relatively few when compared with other conditions. However, due to the high cost of MS DMTs, the Society would encourage consideration of drugs that have high costs but relatively lower utilization to ensure that people living chronic illnesses such as MS are able to access and afford their physician-prescribed medications.

Affordability review outline and elements

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 state,
- Average cost to state health plans based on typical patient access to a drug,
- Impacts on patient access resulting from cost of drug and insurance benefit design,
- Average patient's copay and/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.



**National
Multiple Sclerosis
Society**

Multiple sclerosis DMTs and generics

Brand name drugs of MS DMTs had a median price of over \$107,000 as of February 2024. When we discuss the cost of MS DMTs, we are not just talking about products new to the market. There are now over 20 DMTs on the market to treat relapsing-remitting courses of MS. 12 have been on the market for at least a decade, some of those for even longer. 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.

Generic drugs have a role in driving down high prices and making medications more affordable. However, as we see within the MS DMT class, the existence of generics alone does not guarantee affordability for people who rely on these medications. Today, there are generics for five brand DMTs. While the generic prices have dropped considerably since introduction into the market, people with MS are struggling with affordability, largely because of their formulary placement.

People living with MS do not get to choose which generic is used to fill their prescription which can affect affordability. The generic dimethyl fumarate, for instance, ranged in price from \$1,369 to \$4,258 and the fingolimod generics ranged from \$2,679 to \$27,022, annually. These generics are often placed on specialty tiers with high co-insurance rates, making them as financially out of reach as their brand alternatives. Additionally, most MS DMTs, especially the most widely prescribed, are dispensed primarily via specialty pharmacies, specialty mail order, or infusion centers based in either a hospital or other medical facility.

Therapeutic equivalents and alternatives

When considering therapeutic equivalents - or biosimilars - the Board should keep in mind that for some chronic illnesses, including MS, there has been little research done on multi- or cross-switching and its impact on patients. Because of the lack of clinical evidence around the safety of multi-switching, many experts in the field recommend against the practice until more research is done.

Individual out-of-pocket costs and manufacturer assistance programs

Individual out-of-pocket costs are but one element within our complex drug pricing and health care system. The Society advocates that the Board consider total member cost, not just at the point of service, but holistically to include deductibles, copays, and patient assistance programs related to the specific prescription medication. Several manufacturers of MS DMTs offer application-based, time-limited financial assistance. These programs, however, are tightly controlled, often in limited duration, and do not assist all users of a prescription drug. Because of this, patients cannot necessarily rely on access to those programs from year to year and may see steep increases in cost. The Society encourages the Board to reference any costs before the application of the



**National
Multiple Sclerosis
Society**

manufacturer assistance is applied. This will give a better and more realistic picture of costs to the state for a specific medication.

Advisory committee and stakeholder involvement

The Board advisory committee should have ongoing and continual interaction, involvement, and feedback into drug selection and process. The Society looks forward to this newly appointed stakeholder committee's work and its direct, expert input into the overall Board work and drug review process. The Society will continue to monitor and engage in this process. Upon the Board and advisory committee having specific prescription drugs for review, the then to-be-appointed drug-specific stakeholder committee should provide a direct avenue for patient and patient advocate voices.

Eligible drugs list methodology and data

The Society supports review provisions that enable the Board to look at the full picture of the drug pricing and healthcare system, including both wholesale and out-of-pocket costs. The Society is pleased to see a wide range of data within the proposed methodologies and review criteria and continues to be supportive of review considerations which include:

- Average monetary price concession, discount, or rebate the manufacturer provides to health plans (expressed as a percentage of WAC),
- Total amount of the price concession, discount, or rebate the manufacturer provides each pharmacy benefits manager (PBM) for the drug (expressed as a percentage of WAC),
- Average monetary concession, discount, or rebate the manufacturer provides to health plans or PBMs for therapeutic alternatives,
- Cost to health plans based on typical patient access to a drug,
- Impact on patient access resulting from cost of the drug and insurance benefit design,
- Average patient copay or other cost-sharing amounts, and
- Any other information the manufacturer would like to provide or other factors the board determines it may need.

People with MS cannot wait, and the system must change to strike a better balance between access to innovative therapies and affordability. We thank you for your attention to these important and complicated issues. The National Multiple Sclerosis Society is committed to working with you to find solutions for people living with MS.

Respectfully,
Seth Greiner
Senior Manager, Advocacy
Seth.Greiner@NMSS.org